

ANNEXES

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ANNEX 1: Counselling - Quotations and codes

A list of excerpts as directly coded and extracted from the studies is provided

Facilitators in patients and providers communication

Table 1 - Humanisation of care

	<i>It's so important to have someone talking to you, giving you peace of mind while you are surrounded by machines, someone who doesn't give you injections like you were an apple instead of a patient.</i>
	<i>we are helpless and we need a holding hand, human warmth</i>
	<i>they are always asking how you are, it's a very humane</i>
	detailed explanations on diagnostic procedures and treatments
	Uncomprehensible scientific language was avoided
	Possibility of feeling heard
	professionals provided to patients the telephone number and e-mail of the department. Patients preferred this method of communication because of its speed and effectiveness to consult occasional topics and have the possibility of making 'extra' queries to clarify doubts
CO01 Sacks, A. Abt et al. - 2016	<i>You see them (referring to nurses) every day at the hospital and you know you can call them at any time</i>
	<i>committed to health care. Your health care</i>
	<i>Many people told me that I was in good hands. I was with one of the most well-knowns surgeons here</i>
	stability in the staff of professionals
	having always the same physician
	Accessibility, availability and continuity
	<i>They helped me a lot, making things easy for me, always telling me the truth, showing me their affection</i>
	the patient as a whole
	<i>Cancer is a terrible word</i>
	how important is for patients to be cared for in a humane manner
CO02 Dellasega, Cheryl et al. - 2011	as a person
CO05 Mota, Lorena et al. - 2015	exposure to migrant health topics in medical school, diagnosis & treatment of common diseases in recently arrived migrant
CO06 Graves, K. et al. - 2011	African American women might gain a sense of empowerment through the knowledge gained during genetic counseling
	<i>he never heard back from her gynecologist</i>
	<i>No one from his office ever called me. He never called me. He didn't once check my results from the biopsy</i>
CO08 Dowling, Joni E. - 2010	comprehensive breast care center referred her to a breast surgeon, oncologist, and radiation oncologists
	<i>did not feel comfortable with the oncology radiologist at the other hospita</i>
	arranged for her to be part of a clinical study
	<i>worked proactively for her and made sure things fell in place so she could focus on getting wel</i>
	<i>too many physicians treated the body and left the mind and soul untouched</i>
	peaceful, private environment

	[Table 2. Overall Patient Care Themes as References by Participants] Better communication Teaming approach Tailor feedback solicited Research and information Comprehensive system Robust network of survivors Importance of mind and body
CO10 Burridge, Letitia H. et al. - 2011	a relationship [...] allows a lot of these issues to be monitored and raised as they go along
CO21 Berry, Judith A. - 2009	shows empathy How do you feel
CO29 Reimann, Swantje et al. - 2010	empathetic humane seeing the patient as an equal partner or as a person and not as a number approachability and friendliness shows compassion Personal attention compassion Punctuality brief waiting periods emphasis on the patient, no interrupting phone calls, equal service for all patients, shorter waiting times for emergencies
CO38 Duineveld, Laura A. M. et al. - 2016	to monitor psychological symptoms and to offer support
EN02 Browne, Annette J. et al. - 2012	Revisioning time Attention to styles of communication (both verbal and non-verbal) efforts to provide services (where possible) in local languages adapting clinical practice guidelines in ways that align with the priorities of patients' lives (which can be chaotic or stable at various times) health care encounters can offer high impact ways of recognizing people's vulnerability and foster trust as an essential component of access to PHC racism, discrimination, stigmatization, and social exclusion can be achieved by conveying unconditional positive regard for patient Actively countering the impact of intersecting oppressions requires policies that support a low barrier health care environment wherein patients are, as one staff member described, "just allowed to be". Trauma and violence-informed care, therefore, requires that PHC organizations integrate comprehensive and continuing education for all staff (including receptionists, direct care providers and management) about the health effects of trauma and the principles of trauma- and violence-informed care, and about strategies for actively minimizing the risk of re-traumatization the socio-spatial environments of health care are being conceptualized as relational spaces that can be intentionally designed to support people's subjectivities and experiences (...) <i>they know you by name</i>
EN15 Maten-Speksnijder, Ada J. et al. - 2016	Monitoring patients' treatments' meant that NPs checked the progress or regress of the diseases and the development of complications The NPs usually started the consultation with a single question: 'How are you?' In the interviews, the NPs explained this question is the perfect way to get insight into patients' problems Start with an open question, but no further exploration of patient experiences

	<p>she tries not to lose contact with her patient by asking the girl about school.</p> <p><i>A safe space is where you come. You're not judged. It's free. No one's going to hurt you. We have food, clothing, shower, anything</i></p> <p>By providing a space for leisure, safe spaces enabled discussions about public health messages related to black male sexuality, perceived HIV risk, and perceptions about being socially targeted as dangerous because of their race, gender and socioeconomic status</p>
EN19 Garcia, Jonathan et al. - 2015	<p>Not being "boxed in" also meant collectively developing and articulating a critique of public health discourse that "equates being a black gay man with being at-risk or promiscuous", which men discussed as stigmatizing.</p> <p>supportive for confronting stigma related to sexuality, race, and HIV</p> <p>the utility of "safe spaces" to derive not simply from their role in increasing HIV and STI testing rates, but also, crucially, because these spaces offered "important opportunities to socialize in a welcoming environment" and provided a platform to "talk about issues like racism and sexuality" and to "fight marginalization."</p>
EN24 Powell, Rhea E. et al. - 2016	<p><i>The doctor is just focusing on my medical needs and not focusing on my life issues or... looking at me as a human being."</i></p> <p><i>What doesn't work is when you go in a room, when you meet a patient and you treat that patient as if that patient is a patient, which it is, but different than a social worker coming into the room</i></p>
EN32 Hogden, Anne et al. - 2012	<p><i>... The client might say 'I want to stay home, it's the only thing I want to do', and the partner might be going 'There's no way I can handle, physically, their behaviors'. So you've got to take both into consideration</i></p> <p><i>There's so much family friction at times</i></p>
EN36 CLOCHESY, JOHN M. et al. - 2015	<p><i>And the nice thing about having the same doctor is she knows my partner. She knows how long we've been together and she knows our lives are intertwined. So if something is like out of sync in his, she'll ask me how it's affecting me</i></p> <p>the importance of feeling that their provider truly cared about them</p> <p>it made me feel good because it made me feel like she actually cared</p>
	<p>staff raised issues about how best to perform within changed systems and the emotional work required 'to do the right thing'</p> <p><i>she treats me as a person</i></p> <p>Little things get forgotten</p> <p><u>Service users' experiences of good care</u></p> <p><u>Mental health conditions</u></p> <p>Service users' experiences of good care</p> <p>Communication: information and explanation</p> <p>Good quality listening</p> <p>Not being rushed</p> <p>Assumptions not being made</p> <p>Good communication between professionals and primary and acute sectors</p> <p>Ways in which professionals behave</p> <p>Professionals and key workers going beyond their remit</p> <p>'never giving me the feeling that I am a nuisance'</p> <p>Access to services</p> <p>Access to services when they are needed:</p> <p>offering a safety net</p> <p>Continuity</p> <p>Seeing the same person: not having to start from scratch each visit, which can be painful</p> <p><u>Physical health conditions</u></p> <p>Communication: information and explanation</p> <p>Clear and timely information giving and explanation</p> <p>'If I know what is going on I feel more positive and in control'</p> <p>Ways in which professionals behave</p> <p>Interpersonal skills valued such as 'gentleness', inclusiveness and being respectful of patients and 'to each other'</p> <p>Attitudes of professionals: 'she treats me as a person and takes time with me'</p>
EN38 Ross, Fiona et al. - 2014	

Good care is about having 'time': getting the details right and when 'everything kicks in'
 Individualised and responsive care
 Approach and care tailored to the home environment
 Having someone with an overview
 Involvement
 Feeling involved in my care and in control of myself and my future

'good care' were seen as helping patients to feel happier in themselves with the aim of improving well-being.

caring over a long period of time can set up its own strains in relation to the need to accept the limitations of what is achievable:

[Suggestions]

Communication: information and explanation _(...)

'Treating people like you want to be treated'

For professionals to give time to listen

Access to services

More day care, specialist services, talking therapies and

comfortable environments where people can feel safe (...)

Continuity of care and more face-to-face contact (...)

Individual, whole person, flexible care

Move from being risk-adverse to positive risk assessment(...)

Treating patients as individuals

Taking account of individuals

Involve expert patients in training for health professionals

The 'common denominator is training' (...)

Flexible access to services

Individualised and responsive care

Put 'people first'

'Treat patients as individuals and with dignity'

ED10

Costello,

Joanne F. -

2013

I think that somehow they have to admit their vulnerability in some aspect so that people know that they make mistakes, too. That's pretty important.

ED12 Caine,

Vera et al. -

2016

For many, many years, we were treated like little tokens ... and if we accessed them [HIV health services], then that meant funding dollars. I don't know if I should call it grassroots or to the human side of it, that's what these guys [nurses] have shown me, "Oh, yeah, I'm human! Okay, you can actually touch me!"

ED14 Vega,

Gema et al. -

2014

Well, I have a GP who's there for me, you know, so I am lucky there, too lucky. I have such a good GP in that regard. He listens, everything I ask him, everything, he answers, and I can't do any more.

Table 2 - Communication as care

CO01 Sacks,

A. Abt et al. -

2016

human touch, interpersonal and communication skills

empathy, kindness, friendliness, affection, cordiality, proximity, warmth, discretion, sensitivity, commitment, dedication, sympathy, good humour, trust, support, company, tranquillity, dialogue and listening, being attentive, recognising and remembering the patient

people there **supporting**

	<p>They keep an eye on you</p> <p>personalised</p> <p><i>they addressed me as 'Amanda'</i></p> <p><i>received wonderful, loving care, with lots of affection</i></p> <p><i>nurses came, asking if I needed anything</i></p> <p><i>always smiling and acting kindly</i></p> <p>affectionate</p> <p><i>I have no complains, I've been very lucky</i></p> <p>people always smiled at me</p> <p>comfortable</p> <p>good professionals, very nice people</p> <p><i>nurses where lovely</i></p> <p>jokes</p> <p>cheering people up</p> <p><i>nurses were very affectionate</i></p> <p><i>it's so important to have someone talking to you, giving you peace of mind while you are surrounded by machines, someone who doesn't give you injections like you were an apple instead of a patient</i></p> <p>warmth many nurses show</p> <p>Personalised care, information and advice</p> <p><i>They always told me the truth</i></p> <p><i>they dealt with me with loving care</i></p> <p>Fluidity in the communication</p> <p>kindly and professionally</p> <p>clearly</p> <p>honestly</p> <p>truth</p> <p>very loving, very tactful way</p> <p><i>jokes from time to time, trying to light things up</i></p> <p>clear, calm manner</p> <p><i>he provided me such shocking information in a way that made me feel reassured, protected</i></p> <p>relationship of trust and security</p> <p>a delightful man</p> <p>coordinated with patient associations and support group</p> <p>With the exception of how they dealt with the diagnosis at the beginning</p>
CO02 Dellasega, Cheryl et al. - 2011	<p>were more at ease with the nurse because of how they approached them and paid attention to them during their visits.</p> <p>the nurse had time to discuss the patient's failure to monitor and listen to the reasons why the patient had stopped</p> <p>the DYNAMIC nurses offered them guidance and support and did not dictate to them what they should do.</p> <p>the nurses understood what they were going through and so they were more receptive to the nurses' comments and suggestions</p> <p>Non-judgemental</p> <p>Being heard</p> <p>responded</p> <p><i>looking me straight in the eye</i></p> <p>Encouragement</p> <p>empowerment</p> <p>empathy</p> <p><i>encouraging</i></p> <p><i>d she's very reassuring. Everything that she explains to you</i></p> <p><i>it's in the way she presents it. .it's kind of a laid back manner, not standoffish or a lecture.</i></p>

	<i>keeps me motivated</i>
	<i>'She's very positive about everything y</i>
CO04 Delea, Sarah et al. - 2015	need for emotional support alongside the medical management
	understanding, empathy, reassurance and communication
	I'd like to be reassured by the doctor.
	building a good rapport with health care professionals was an important aspect of the care process
CO06 Graves, K. et al. – 2011	It empowers people to find out t allows them to play an active role
	clarity
	<i>...I try to encourage them [African American women] to talk and ask questions... give them the information try help them decide</i>
	Providers saw their role in the genetic counseling and testing process as agents of information genetic counselors and medical oncologists were more likely to refer to themselves as having a specific role in the genetic counseling and testing process compared to providers from their specialties.
	Medical oncologists were more likely to mention their role in communicating the importance of genetic counseling
	genetic counselors saw their role as primarily educating patients about their objective level of risk based on family and personal history and helping them understand the meaning of genetic test results
	Cancer providers mentioned their role as initiating a conversation about genetic counseling and testing
	innate fear of genetic
	<i>Sometimes, we follow up sort of informally when I see them back, but I'm not sure if we have a real sense I give them the contact information</i>
CO07 Alexander, Stewart C. et al. - 2012	checked patient's understanding of information
CO08 Dowling, Joni E. - 2010	his response was proactive and he sought out medical opinions from Vanderbilt University
	He told her not to be concerned about it, but would have her go for a diagnostic mammogram.
	He kept saying it was nothing, but would do a test to rule out breast cancer.
	could ask
	Everyone worked at the same hospital, so communication among her physicians was good.
	received patient questionnaires in the mail after treatment and considered her cancer treatment center to be actively seeking patient feedback
	received a written survey from her cancer treatment center
	regular patient relations
	received phone calls
	asking for her opinion about the quality of care
	cancer treatment centers to better communicate the initial diagnosis of breast cancer
	provide more information on topics such as preventing side effects of treatment, to offer research findings on effects of cancer drugs and fertility
	to distribute a recommended list of Internet Web sites.
	beforehand
	discuss preventive measures to reduce the risk of developing lymphedema.
	wanted physicians to listen to their patients
	emotional attachment

<p>CO09 Laws, M. Barton et al. - 2012</p>	<p>friendship provider knowing about their personal lives and struggles <i>are very interactive; he wants to know</i> <i>He's compassionate, he's a regular guy.</i> provider being accessible home-phone or a cell-phone number for their provider the provider being available promptly availability of nurses for telephone He's got my number. I got his number. I could call him for an emergency and talk to him, If he's busy, he'll call me back off his pager. <i>I can talk to him about anything, sexual or health-wise</i> continued support from their providers was a factor in making or sustaining change clarity and directness perceived accuracy of the content of the provider's message She's seeing that fact in the history that he's going down below 200 and the doctor getting upset about that is very, very understandable. They're in this business to save lives, not lose lives.... I don't think she was rude, I think she was giving him tough lo I would have went it and shocked him to the point where it's like let me really think about what my life is and where it's going. She should be encouraging and explain what good things would happen with the medicine t they should tell you what is gonna be the side effects if you don't do it</p>
<p>CO10 Burrige, Letitia H. et al. - 2011</p>	<p>caregivers may see no genuine reason to engage with their GP A GP's genuine inquiry may, paradoxically, produce an unappreciative response GP walks in order to convince caregivers that they are genuine patients with genuine health concerns They think it is going to take too long. Patients are often very considerate of their doctors To engage meaningfully with a caregiver, busy GPs must choose between limiting the length and scope of a consultation and opportunistically raising important issues which generate waiting room delays The GP would have to know the [caregiver]. <i>would do everything possible to try and help us out</i> <i>to proactively cultivate a relationship which allows the opportunistic discussion of any issues that may need to be considered</i> I have always been surprised at how well they cope and how little help they ask for Nonverbal cues are important, body language <i>treats you like you are the most important person in the world</i> empathy and anticipation are acquired skills acknowledging quite clearly that they have a role in supporting the family member Making the environment comfortable initiat[ing] the topic themselves by just asking how they are managing and how they are feeling give them some information about what resources are available <i>The one thing you can never fake in general practice consultation is the time you spend</i> <i>It takes time to address these issues. It takes time to allow people the opportunity to think and bring areas up so I often find it happens much more readily in the home environment.</i></p>
<p>CO11 Meyer, Samantha B. et al. - 2012</p>	<p><i>he's always explained</i> <i>he's gone into details.</i> <i>doesn't write anything off without doing tests for, for further examinations—whatever.</i></p>
<p>CO13 Venetis, Maria K. et al. - 2018</p>	<p>the nouns and nominalizations, have been associated in previous studies with informational discourse in studies examining differences across types of spoken discourse, nouns and nominalizations are much more frequent in informational spoken discourse (e.g., broadcasts, nurse-patient interactions) than in more interpersonally oriented discourse (e.g., face-to-face conversation)</p>

	<p>frequent use of third person (it) provides a way of generalizing about the patient's condition rather than personalizing it to the patient's case. I</p> <p>The addition of the second block, adding impersonal information provision, yielded significant change, $\Delta R^2 = .05$, $F(4, 46) = 36.60$, $p < .001$. Pre-visit anxious occupation positively ($\beta = .77$, $t = 10.25$, $p < .001$) and education ($\beta = -.19$, $t = -2.55$, $p = .01$) and impersonal information provision ($\beta = -.22$, $t = -2.94$, $p = .005$) negatively influenced post-visit anxious preoccupation.</p> <p>very specific communication-based participation behavior of provider impersonal information provision has the potential to improve patients' psychosocial health outcomes</p> <p>Results showed that nominalizations (e.g., information, radiation), concrete nouns (e.g., device, drug, machine), and group nouns (e.g., hospital, lab), when in combination, were associated with improved outcome variables (lower post-visit anxious preoccupation, higher treatment plan satisfaction, higher intention to adhere</p> <p>more detailed provider provision of information</p> <p>Patients may prefer instances when providers offer this information without patient needing to request the information, promoting patient-centered care. Furthermore, it follows that patients would be less anxious post-consultation</p> <p>acquired detailed knowledge that minimized their uncertainty</p> <p>it is associated with interactive contexts, where the speaker and hearer have shared knowledge about a topic. However, it also brings an impersonal focus to the discussion of patient's condition and treatment options. Rather than focusing on the patient herself (e.g., you, your, etc.), in the interactions with higher scoring outcomes, the provider focuses on processes related to the diagnosis and treatment of breast cancer and, when people are involved, an abstract they.</p> <p>when discussing the details of the patient's case, the language is often impersonalized through the use of it or they</p> <p>this use of impersonal language in discussions of the patient's treatment options may allow the patient to focus more objectively on her options and thus leave her feeling more empowered to make a decision</p> <p>Use of impersonal language may reduce anxiety and increase intention to adhere and satisfaction with the treatment plan by shifting the patient's mindset from breast cancer as an unexpected and unmanageable disease to evaluating breast cancer treatment as commonplace and routinely successfully performed</p> <p>The use of because is the most frequent way to indicate a reason for taking an action in discourse and used to create arguments</p>
CO14 Hersch, Jolyn et al. - 2013 et al. - 2013	<p>preferred to be given balanced information</p> <p>"I think if you've got the information, it should be provided."</p> <p>women are entitled to know</p> <p>women recognised the challenge posed by trying to communicate the complex information format that would be accessible and more practical</p>
CO15 Hart, Ruth I. et al. - 2017	<p>Patients wanted professionals to initiate regular discussions: <i>It would be great if the consultants did say to you "And how are your fatigue levels?"</i></p> <p>patients should be warned that in the short-term their sense of fatigue might even increase obvious importance where interviewees had not previously connected fatigue with their condition</p>
CO17 Garon, M. - 2012	<p><i>Learned at home – I was always taught to speak up</i></p> <p><i>hats not everyones culture (speaking up) and some people have been told not to speak up in</i></p> <p>growing up</p> <p><i>school, I was forced to speak up</i></p>
CO19 Brez, Sharon et al. - 2009	<p>time</p> <p>workload</p> <p>knowledge and confidence</p> <p>expectations and attitudes</p> <p>Use of "effective communication,</p> <p>"ongoing phone advice", "diabetes passport".</p> <p>ongoing applied learning</p> <p>Misalignment of patient and PCP attitudes and expectations related to self-care behaviours, treatment targets, And responsibility for diabetes care,</p>

<p>CO20 MacDonald, Kath et al. - 2015</p>	<p>you're there for 21/2 hrs, you're stuck in a room</p> <p>patient trusts nurses</p> <p>Nurses treat you like a person</p> <p>trust</p> <p>respect</p> <p>knowledge of young people</p> <p>Acceptance of YP's experiential knowledge</p> <p>values</p> <p>beliefs</p> <p>experience</p> <p>expertise</p> <p>Relationship-building</p> <p>personalities</p> <p>building rapport</p> <p><i>I would err much more on the side of listening</i></p>
<p>CO21 Berry, Judith A. - 2009</p>	<p>opinions</p> <p>suggestions</p> <p>instructions</p> <p>seeks patient ideas</p> <p>social conversation or greetings</p> <p>shows approval</p> <p>asks for the patient's opinion, understanding</p> <p>NP used information-giving at least as much or more than information-seeking i</p> <p>Every NP used information-giving and information-seeking</p> <p>only 16 NPs (30.2%) used a patient-centered communication style, 37 (69.8%) used a provider-centered communication style</p> <p>used information-giving slightly more often than information-seeking</p> <p>Thirty-seven NPs (69.8%) used partnership-building</p>
<p>CO23 Davies, Jane et al. - 2014</p>	<p>ability for people to speak honestly and in detail about hepatitis B was felt to be culturally difficult between individuals of different gender</p> <p>health care professionals felt that consultations between a health worker and patient of the same gender tended to result in improved cross cultural communication and improved rapport</p> <p>the importance of telling the full and true story</p> <p>not missing out the details, but finding a culturally appropriate contextual translation to allow a shared understanding of the important information</p> <p>people living with CHB and community members perceived that the moral and ethical obligation was on "us", the health care providers, the ones giving injections (vaccination) and taking blood tests to ensure patients were appropriately informed</p>
<p>CO27 Dolce, Maria C. - 2011</p>	<p>my oncologist was grateful to have the help from an online group</p> <p>Participants endorsed healthcare providers who were willing to take the time to answer questions or were inclined to communicate via e-mail.</p> <p>endorsed specialists from major cancer centres of excellence for superior care and outcomes.</p>
<p>CO29 Reimann, Swantje et al. - 2010</p>	<p>personal skills of the doctor such as patience, taking the patient seriously, being friendly, caring, trustworthy, diligent, empathetic and humane.</p> <p>s seeing the patient as an equal partner or as a person and not as a number,</p> <p>patient-centeredness</p> <p>showing interest in the patient,</p> <p>spending enough time with the patient</p> <p>communicative skills include above all effective listening, appropriate questioning and the provision of information</p> <p>Interpersonal qualities are seen more in the establishing of a trusting relation</p>

	<p>ability to listen to communicate</p> <p>there is some concrete overlap between the dimensions of communication and doctor-patient relation</p> <p>caring</p> <p>Spending enough time with me</p> <p>following up as needed after my visit</p> <p>Helpfulness</p> <p>Friendly</p> <p>approachable</p> <p>time</p> <p>show concern for you</p> <p>MD follows-up on any problems or concerns you have</p> <p>professionalism</p> <p>they make you feel comfortable</p> <p>Knowledge of medicine</p> <p>Explanation/Coordination of medications</p> <p>humaneness</p> <p>availability by telephone</p> <p>doctor's availability by telephone</p> <p>outside of visiting hours</p> <p>the most frequently represented dimensions in PRSs include diversely operationalized ones such as professional competence and doctor-patient relationship</p>
CO31 Zulman, Donna M. et al. - 2015	<p>communicating with providers across different settings,</p> <p>Virtual clinic visits</p> <p>e-mail or secure video-conferencing</p> <p>Patients expressed great interest in technology that would facilitate communication with multiple providers</p> <p>Many patients were interested in technology (including secure messaging and video-conferencing) that would facilitate communication and coordination with multiple providers across different health care systems.</p>
CO32 Greenhalgh, Trisha et al. - 2010	<p>Despite personal invitations, letters, posters, and "what's new" messages on practice websites, fewer than 100 patients (of a combined list size of around 30 000) in the three participating practices expressed an interest in using the Communicator messaging function over a six month period</p> <p>One thought that Communicator had given them "a fulltime personal GP all to myself.</p> <p>For many, emotional continuity with "their" general practitioner was more significant than transfer of particular items of knowledge or advice</p> <p>Some thought that emailing their general practitioner directly enabled them to bypass a busy appointment system or negotiate treatment that would otherwise be against the rules</p> <p>Others felt uncomfortable using Communicator, used it rarely, and were concerned that they might offend the doctor</p> <p>intrude on his or her private time: <i>I know myself how emails encroach on your time, my gut reaction is how is the doctor going to cope with this workload?</i></p>
CO33 Vilhauer, Ruvanee P. - 2014	<p>Time</p>
CO36 Wilkinson, Emma et al. - 2014	<p><i>At present my Doctor is excellent, I am able to talk to him and ask questions whereas the previous one I couldn't</i></p> <p><i>The nurse is very good</i></p> <p>'chit chat', which could usually be used to reinforce the principles of rehabilitation and to understand the life goals individuals would find meaningful.</p>

CO37 Taylor, Elizabeth et al. - 2014	<p>informal chat is often part of their therapeutic communication.</p> <p>They expressed feeling highly skilled in use of communication to educate, maintain engagement and promote autonomy, but found it harder to use subtle means of building a therapeutic relationship when faced with a language barrier</p> <ul style="list-style-type: none"> • Building a relationship • The third person • Non-verbal communication <p><i>How important the subtleties in language are, and how missing out on those stops you building up a really good rapport with your patients, and how it might affect your therapeutic relationship with them</i></p> <p><i>we're kind of checking people's motivation, checking they're engaged in therapy ... making sure that we're using all of those skills that we've got to try and keep motivation up</i></p> <p>feeling skilled in using non-verbal communication</p> <p>when a language barrier was not present, they utilised subtle forms of communication when negotiating goals and engaging people in rehabilitation</p> <p>Being an effective therapist is about being able to communicate effectively and being able to read people from the interaction between people in communication</p>
CO38 Duineveld, Laura A. M. et al. - 2016	<p><i>What matters is: "How are you? Do you have any ques- tions? Are there any uncertainties?" This is a reason for us to get in touch with patients.</i></p> <p><i>I think that psychological support will be easier to provide if you're also involved in the physical part of survivorship care</i></p> <p>Another argument of GPs to be willing to coordinate survivorship care is that they felt they were more aware Of patients' contexts than were medical specialists</p> <p><i>we have to adopt a different role, as a coach and not as a father figure.</i></p>
EN01 Ekundayo, Olugbemiga T. et al. - 2012	<p>positive provider staff attitude towards the men</p> <p>effective information</p> <p>dissemination through constant reminders</p>
EN02 Browne, Annette J. et al. - 2012	<p>what might be seen as excellent interpersonal communication in one cultural context might be seen as discriminatory or alienating in another.</p> <p>Actively counter the impact of intersecting oppressions on health, access to care, and quality of life</p> <p>providers and organizations need to be aware of how marginalizing practices and social exclusion operate in structures and institutions, including health care, thereby shaping people's health care experiences and access to service</p> <p>respect and acceptance to individuals</p> <p>attending to power differentials, is highly significant, particularly for people who experience social exclusion</p> <p>Affirming approaches</p> <p><i>I'll stop and have a small conversation with the person, or I'll say, you know, I'm really happy to see you here today</i></p> <p>accepting, non-judgmental</p> <p>some people's behaviours approached a disruptive level, staff (usually receptionists) respectfully used communication styles to diffuse tensions and set limits, which were usually respected</p> <p>creating a safe environment based on an understanding of the effects of trauma, so that health care encounters are safe, affirming and validating</p> <p><i>Or how difficult it was for that person to actually bring up their concern to you... getting into conversations around our table about power imbalances and about how our interactions [with patients] can really affect this.</i></p> <p>must take into account the effects of working with highly traumatized patients,</p>
EN03 Locock, Louise et al. - 2011	<p>extra time and rapport with staff</p>
EN05 Graffigna,	<p>Psychological support for elaborating and accepting the diagnosis[...] better self image [...]</p> <p>avoiding isolation and constructing good social relationships [...] Motivational interventions [...]good doctor-patient relationship [...]To feel 'guided')</p>

Guendalina et al. - 2014	
EN05 Graffigna, Guendalina et al. - 2014	<i>I have periodical meetings with the doctor, but I need a more direct way of communication</i>
EN06 Walters, Chasity Burrows - 2013	participants described how direct communication about safety concerns either prompted or enhanced their awareness of safety issues. In most cases awareness of potential safety issues had been communicated directly by the nurse HCPs have a duty to protect patients from harm They described the criticality of always having access to direct communication with their HCPs, such as that afforded by the nurse call button they don't always come as fast as you want them to the importance of the HCP inviting patient involvement
EN07 Hout, Marie Claire Van et al. - 2012	<i>I am optimistic and open to it, however the overarching feeling of stigma against junkies needs to be realised, and can be viewed negatively with a patronising view.</i>
EN09 Flournoy, Minnjuan W. - 2011	<i>Sometimes when I haven't seen a patient in a long time or had a hard time getting in contact with them, we have so much to talk about and catch up on, and sometimes dental just doesn't make it.</i> Communication with patient clinicians especially highlighted establishing with patients that they could be completely open and honest with no condescending responses. Calling patients between visits just to check up on patients to ensure all was well b <i>They don't talk down to me – they talk to me on my level</i> <i>they don't use all these words I don't know what they mean or don't make sense to me.</i> We want patients to talk to us – to ask questions... <i>Try to be open to that person and let them know they can discuss any of their oral health problems with me</i> brochures I talk to the patient on their level a friendly staff members that quickly addressed any concerns positive open <i>They're always really nice when I talk to them on the phone and in person, very open. I like that – they're positive nice and friendly with patients</i>
EN10 Brooks, Fiona - 2008	nurses were certainly encountering a detailed and probing form of questioning style, but not an aggressive, combative mode. Those stories had a real impact on me, I have been in nursing 17 yr. and never heard them before
EN14 Hirjaba, Marina et al. - 2015	correct and clear information in comprehensible language, with advice, and counselling tailored to individual needs. tell to me in an understandable way about what can happen A good relationship with patients was described as professional, having a positive, non-paternalistic attitude and being compassionate and friendly truly listening manifesting a real interest in the patient's physical and mental well-being. support and encouragement they received from healthcare professional
EN15 Maten-Speksnijder, Ada J. et al. - 2016	<i>[Patients] want to talk and after one open question they tell their problems, which could be anything. Such as: not being able to Accept the disease or doing exercises, worrying about nutrition, a divorce, just anything</i> Prioritising treatment in daily living Interacting socially Stimulating to live as healthy as possible

	<p>Instruction is often used to stimulate patients to control symptoms</p> <p>Coaching of patients' goal-setting to deal with consequences of the disease sometimes</p> <p>The patient puts her notebook on the table, '<i>here are my results</i>'. '<i>Let's have a look</i>'</p> <p>Together they discuss the findings.</p> <p>social interaction with the patient</p> <p><i>'this is the first time we meet and as a nurse I support you in bearing the consequences of the radiotherapy, which are quite heavy. So, I have the same question I always ask: how are you?'</i></p> <p>The NP's explanation of the origin of the symptoms transformed Ann's dismissive attitude into openness.</p>
EN16 Holmberg, Christine et al. - 2015	Someone is watching over you , someone takes care of you and makes sure you are taking all of your appointments.
EN23 Davies, Freya et al. - 2014	totally clear to them
EN24 Powell, Rhea E. et al. - 2016	<p>increased health system outreach to better identify community-specific needs and to establish partnerships between communities and health providers would strengthen community trust.</p> <p><i>I always say take it to the streets because that's where they are is in the street and to let them know that you care enough to walk the street to let them know this is what's available to you lets them know that you care</i></p> <p><i>I think doctors can become better listeners. I think people know their bodies...</i></p>
EN30 Cook, Erica J. et al. - 2014	<p><i>I'm dyslexic so it is better to see a doctor if I am ill so we can understand each other</i></p> <p><i>They give you immediate feedback on what you need to do when you are in that situation</i></p> <p><i>had some negative experiences that related to the amount of time it took to be called back by a nurse, and the time of day that they were called back e.g. being called during the middle of the night</i></p> <p><i>NHS Direct have taken 8 hours to phone me back I could have had an appointment in that time</i></p> <p>distinct preference for instant face- to-face healthcare</p> <p>she has said it has been quicker to find a doctor and the doctors come out quicker than that because when her mum is bad she can't be spending 10 min on the phone'</p> <p>NHS Direct is more instant if a person does have a problem</p> <p>Conversely, 'non-users' from both Manchester and Mendip outlined an overarching preference for face-to-face health- care.</p> <p>face-to-face is really important because this is what reassures you and this has to be the best option</p> <p>physical symptoms are important aren't they so I think it's very necessary to see a doctor face-to-face' (</p> <p>an individual could express themselves through body language. It was also more personable when speaking to someone face-to-face.</p> <p>to see someone and you talk to them you can see them and see them smiling at you and treated sympathetically but on the phone it's different you don't se</p>
EN32 Hogden, Anne et al. - 2012	<i>The information is important, but the time that you give the information will be also important, because you might give too early, and they forget or don't hear what you said</i>
EN32 Hogden, Anne et al. - 2012	<i>It's about trying to be responsive to them when they are ready to hear. So I think having good information to hand, being as responsive as you can.</i>
EN35 Gien, Lan et al. - 2017	<p>cultural consideration and local context</p> <p><i>take the time to listen and alleviate my fears.</i></p>

<p>EN36 CLOCHESY, JOHN M. et al. - 2015</p>	<p>provider should give them the courtesy of fair, equitable time to discuss their personal health issues,</p> <hr/> <p><i>He asked me what I wanted to accomplish by us meeting. He listens. We don't, even though it's like an hour, I never feel rushed and I just believe that had I not left the other people, I know I never would've found this person. It makes me feel good because things that I had on my mind or needed clarification or answers</i></p> <hr/> <p>provider that listened and processed the health information</p> <hr/> <p><i>I introduced myself, I introduced my partner, gave the two-page typewritten information. He read it all. He asked questions as he read it, if there were things that he did not understand</i></p> <hr/> <p>importance of open communication with the provider listening as closely as the patient listens by saying,</p>
<p>EN38 Ross, Fiona et al. - 2014</p>	<ul style="list-style-type: none"> • Communication: information and explanation • Good quality listening • Not being rushed • Assumptions not being made <hr/> <p>Ways in which professionals behave Interpersonal skills valued such as 'gentleness', inclusiveness and being respectful of patients and 'to each other'</p> <hr/> <p>Attitudes of professionals: 'she treats me as a person and takes time with me'</p> <hr/> <p>Good care is about having 'time</p> <hr/> <p>treating patients as individual people active in their own care, feel safe and supported.</p> <hr/> <p>enough time to express themselves and patience in explaining everything they needed to know without being judgemental</p>
<p>EN40 Rise, Marit By et al. - 2013</p>	<p>bilateral exchange between different proprietors of knowledge expressing both experiences and knowledge about their illness providing knowledge to the patients about illness and treatment</p> <hr/> <p><i>When I'm alone with a patient I think about participation as being a part of your own treatment... knowing as much as possible... having as much knowledge as possible about your own disease ... its about shared understanding and motivation and whether you agree with me or not. And whether you want to try what I think we ought to tr</i></p> <hr/> <p>Service providers described on the other hand the dialogue as a means to exchange information and knowledge to make sound decisions, which included the service users perspectiv</p>
<p>ED4 Blixen, Carol et al. - 2015</p>	<p><i>She always built me up to help me understand that I was doing a good job.</i></p>
<p>ED5 Albarran, Cynthia R. et al. - 2014</p>	<p><i>Promotoras</i> were thought to have several personal qualities that were desirable and motivating such as being patient, trustworthy, friendly, determined and caring.</p>
<p>ED8 Sekse, Ragnhild Johanne Tveit et al. - 2014</p>	<p>a feeling of recognition on receiving information and counselling</p>
<p>ED14 Vega, Gema et al. – 2014</p>	<p><i>I really trust my GP [general practitioner]. Apart from his job, from his profession, he has another job with me, because he is like a shrink. He really listens to me so much.</i></p> <hr/> <p><i>What I mean is that we need qualified people to explain to us all the questions you might have, or a cardiologist, or a GP, yep, or neurologist or whatever.</i></p>
<p>EM01 Agerskov, Hanne et al. - 2015</p>	<p>The healthcare professionals introduced diagnostic test by way of holding a dialogue with the donor. This created distinctness and predictability in the donor and that 'everything was under control'</p> <hr/> <p>The donor looks at the bioanalyst when she asks him something. There is a quiet and reciprocal relationship between them, and the donor reads, listens and answers when asked questions</p> <hr/> <p>generating confidence, motivation and commitment</p>

	the nurse observes and focuses attention on the fact that the donor could be nervous and tense during the clinical examination, and an opportunity to talk about feelings and experiences was created.
	by her body language , the nurse is involved and demonstrates empathy
EM08 NANTON, V. et al. - 2011	<i>They have treated me very nice. I can't complain. If I complain of the treatment that I have....I would be deceiving my own self.</i>
EM11 Nota, Ingrid et al. - 2016	<i>I want to share in the decision-making process. That he listens carefully to what you have to say and that you listen to his arguments as well. And that you can say anything, even small things, without feeling a bore. That's when you have a good relationship</i> Expertise of the doctor highly but wanted to be a part of the decision-making process because they themselves feel their symptoms best, wanted to have some level of control or wanted to critically evaluate the impact the doctor's advice would have on their personal situation and discuss this <i>I want to share in the decision-making process. As a patient, you should follow the doctor's advice, you should not say it is nonsense, you cannot do that, but I do critically evaluate his advice. [...] And if I do not agree or have questions, well, then I discuss this with him</i> <i>When starting medication I prefer to share in the decision-making process. Increasing the dosage is something I want to decide myself, as I'm the one who can best determine how severe my pain is. And the doctor decides if the dosage needs to be decreased, because he/she understands what my blood level results mean.</i>
EM12 Wiljer, David et al. - 2013	Participants indicated that by engaging in collaborative dialogue with the clinician regarding their health condition, it made them feel more supported and cared about, especially during the time when their treatment was complete and many felt 'forgotten about'. SC was a place for them to express their feelings, spend time reflecting on their health condition and consider life issues that had not been address They reported that the SC was a place where they felt individually supported because they were able to speak with the clinician and considered their time together valuable Participants reported feeling comfortable sharing their opinion and discussing aspects of their health condition and trajectory of care with the clinician. Participants were able to reflect on their diagnosis, treatment and strategies for carrying out their goals and were motivated to implement the recommendations given to them by the clinician <i>You take the time...That's the most important thing. We get rushed through by the doctors. Every appointment, it's in and out. The nurse, the student doctor, all come in already knowing everything. It's understandable, they have so many people. It's nice to be able to sit back and talk with [the clinician]</i> <i>I found [the clinician] very easy to talk to...[the clinician] had that sort of personality... was engaging and came across as being interested. That's important.</i> <i>encourages me quite a lot to seek out the program and find out more about it</i> <i>I had a better understanding about who I could turn to for what because it is a little confusing...you do end up having several different doctors...</i> <i>I learned about my cancer, about my stage, [the clinician] helped me understand that a little bit better. I wasn't sure whether that changed with the treatment and [the clinician] helped me understand..."</i> <i>It verified some things...what to expect after some of the treatments, effects on my body, like the exhaustion. I was telling [the clinician] some of the things I was experiencing</i> <i>I already have a pretty good understanding of my diagnosis. I don't think [the clinician] could have really told me anything that I didn't already know</i> <i>we went beyond cancer...[talked about] work stresses and return to work...some help you can get for return to work strategies before you get into that...</i> <i>...fatigue is a huge issue so [the clinician] mentioned that...I was complaining that I was somewhat brain dead...[the clinician] mentioned...good recommendations...</i> <i>There's a lot of confusion about taking care of yourself and how best to do it... Nutrition I feel like is a big one that was not covered</i>

	<i>think [the clinician] had a clear understanding of where I was coming from at that point. [The clinician] really addressed that</i>
EM17 DiGiacomo, M. et al. - 2015	<i>Let's face it, if you've got a female GP, you're lucky really...I find women are better at listening than men</i> within health service facilities and outreach initiatives, health professionals who appreciate the importance of getting a sense of who the person is and what they need and want is vital to providing person- centered care. Increasing capacity for cultural sensitivity in providers new arrival and refugee communities preferred face-to-face outreach and female health workers/professionals. <i>Health workers have to speak up for rights of women even in their own workplaces</i>

Table 3 - Trust as know the trust, reliability, know the full info

CO01 Sacks, A. Abt et al. - 2016	They reported it to be essential that the information comply with their needs and demands and especially be provided gradually in the different clinical meetings
CO02 Dellasega, Cheryl et al. - 2011	patients were empowered with information to make their own decisions and set realistic goals
CO04 Delea, Sarah et al. - 2015	told me the consequences Receiving information from health care staff was "vital"
CO06 Graves, K. et al. - 2011	<i>I remember one [patient] who told me 'I don't want anybody to peek into my private life.'</i> [Another patient] said, 'I think if I find out I have BRCA1 then...I won't get health insurance because of discrimination .'" historically well known for [experiencing] atrocities African American patients oftentimes tend to be more suspicious about [genetic testing] feel it's another way of [labeling them]
CO07 Alexander, Stewart C. et al. - 2012	over 97% of hematologists–oncologists, providing at least one explicit recommendation ('We should get started with thalidomide and dexamethasone in the next few weeks') Recommendations were made based on future possible contingencies Physicians discussed treatments in relation to both curative goals (72% of conversations) ('what takes to cure it is a bone marrow/stem cell transplant and with eight brothers and sisters, you are likely to have someone who will be a match for you') as well as extending life (22%) ('that is a condition we can manage for many, many years with these drugs').
CO11 Meyer, Samantha B. et al. - 2012	<i>the practice I go to, I trust, I trust most of the doctors there</i> she has reservations about trusting all physicians so she specifically chose to see a physician she trusts.
CO13 Venetis, Maria K. et al. - 2018	patients would anticipate high degrees of informational speech from their provider, particularly as this visit is often the first that follows the diagnosis. Research has documented that breast cancer patients have high informational needs these findings suggest a contradiction to contemporary guidelines that urge providers to "limit the amount of information provided" (Weiss, 2007; p. 29) in order to increase comprehension and health literacy . Although this recommendation may provide utility in some medical contexts, it appears that within the breast cancer surgical treatment decision-making visit, patients prefer greater information
CO14 Hersch, Jolyn et al. - 2013	full, balanced information as the most ethical approach to
CO26 Wray, Ricardo J. et al. - 2009	people could easily receive and understand. 'People know you and feel that you are telling the truth.' supporting community conversation about prostate cancer to allay cancer fear.
CO29 Reimann,	allowing the patient to ask whether the patient feels trust in the particular doctor

Swantje et al. - 2010	doctors' knowledge of his or her own (professional) limitations (e.g. prompt referral, collaboration with other doctors, admitting his or her own errors) diligence (e.g. investigating all possible causes, correct diagnosis, thorough examination, responsibility) Privacy well-advised diagnosis later confirmed how well and how transparently the patient is informed during the medical treatment. understandable information about the causes and process of the illness and the side effects of diagnosis and treatment
CO31 Zulman, Donna M. et al. - 2015	User-friendly resources to help patients identify potential med-med and med- condition interaction <i>sometimes you will be more cutting-edge than your doctor because you research it every day because it's something you live with</i> to build knowledge before clinical encounters
CO32 Greenhalgh, Trisha et al. - 2010	how to live with their condition emotional support
CO33 Vilhauer, Ruvanee P. - 2014	Information is at a premium <i>they must know about new drugs and treatments available at any given time and about on-going clinical trials</i> <i>But the people all across the country getting involved in different trials, different treatments, different philosophies about how to handle this</i>
CO35 Goddu, Anna P. et al. - 2015	established trust and a sense of pragmatism
EN01 Ekundayo, Olugbemiga T. et al. - 2012	Symptoms risk factors causes comfort, color, blood and urgency Dissemination of information about health services related to prostate cancer care information on community health outcomes through information surveillance systems
EN02 Browne, Annette J. et al. - 2012	Revision use of time to meet the needs of client Time and its use are crucial considerations, in terms of expectations regarding 'how long' it should take to see health improvements, and how providers use time because it's hard for me to ask for things...it's hard for me to ask for help. So the staff here are patient with that. And I think they understand that, which is important. Openly discussing various approaches to harm reduction people with trauma histories often experience mistrust, building trust is critical to sustaining connections and a sense of personal safety
EN03 Locock, Louise et al. - 2011	Reassurance about treatment decisions Furthering medical knowledge for the common good Reassurance that in good health or early detection of problems
EN05 Graffigna, Guendalina et al. - 2014	<i>It was nice: with videos and patient interviews. I think that something like that could be very useful and should be repeated!</i>
EN06 Walters, Chasity Burrows - 2013	Acknowledging medical errors during the course of a hospitalization was considered counter to the implicit trust the participants felt was necessary between patient and their HCP The term medical error was ultimately recognized by most of the participants, however it was understood not as a complication of disease or treatment, but rather a failure of a human being or system responsibility of HCPs lies in their duty to protect patients from harm, expressed as an implicit trust

	<p><i>If it were a family member or a very close friend, I would want to know every single thing about their case</i></p> <p>targeting her needs and questions may make her more likely to be involved, since she would have less concern about taking HCPs' time unnecessarily.</p> <p>how even with the desired openness on the part of their HCPs their concern about being a burden can overcome their willingness to be involved in their care.</p> <p>There are people that don't know how to make those adjustments though. They can't communicate effectively, it's their way or the highway, and it can't be like that. We all have to be flexible when we communicate.</p>
EN08 Carlisle, Karen et al. - 2017	the presentation of some of that evidence and stats, they were really shocked that it was so significant
EN09 Flournoy, Minnjuan W. - 2011	<p>Dissemination of oral health information</p> <p>transparency in informing the patients of what steps were involved in procedures</p> <p><i>They tell me everything and leave nothing to guess about. They make everything crystal clear,</i></p> <p>clinicians shared in depth information</p>
EN14 Hirjaba, Marina et al. - 2015	Communication was promoted by a feeling of safety, sincerity and trust in healthcare professionals.
EN15 Maten-Speksnijder, Ada J. et al. - 2016	Knowing how medication and treatment outcomes are related to give their patients accurate knowledge about the medicines they take, and how these work
EN23 Davies, Freya et al. - 2014	<p>trust on both sides</p> <p>Doctors described the importance of continuity of care and the trust that needed to be developed between the clinician and patient before they felt comfortable with using this strategy (...) This trust was described as being built over time, knowing that the patient had enough experience with their own disease</p>
EN26 Abma, Tineke A. et al. - 2015	along-the-way trust was build up among a vast group of patients who became owners of the agenda.
EN34 Natale, Anthony P. - 2009	I think that a lot of people respond well to shock factor . Perhaps a ticker (on MSM Web sites) that had statistics like: 20 people died in the last 20 seconds
EN36 CLOCHESY, JOHN M. et al. - 2015	<p>she earned my trust</p> <p>By "trust," participants meant they felt comfortable when 1) they could disclose sensitive information</p> <p>I tell my doctor everything</p> <p>the provider or system would fix their health problem without any strings or barriers attached.</p>
EN38 Ross, Fiona et al. - 2014	If I know what is going on, I feel more positive and in control
ED4 Blixen, Carol et al. - 2015	They didn't hold back the way they felt and we all saw that we had trust in the group
EM09 Grande, Stuart W. et al. - 2013	the word "brother" meant to them, responses highlighted the importance of trust
EM11 Nota, Ingrid et al. - 2016	<p>Trust in their doctor and valuing the expertise of the doctor</p> <p><i>I think highly of the medical profession. I trust them</i></p> <p>Patients who valued the expertise of the doctor mentioned that being well informed, being listened to and having their problems taken seriously were important prerequisites for satisfaction with this form of decision-making: "<i>She decides, but I insist that she takes it... takes me seriously.</i>"</p>

	<p>Most respondents (n=17) preferred shared decision-making (SDM), because it reflects a good relationship with the doctor,</p> <p><i>I want to share in the decision-making process. That he listens carefully to what you have to say and that you listen to his arguments as well. And that you can say anything, even small things, without feeling a bore. That's when you have a good relationship</i></p> <p>expertise of the doctor highly but wanted to be a part of the decision-making process because they themselves feel their symptoms best, wanted to have some level of control or wanted to critically evaluate the impact the doctor's advice would have on their personal situation and discuss this</p> <p><i>I want to share in the decision-making process. As a patient, you should follow the doctor's advice, you should not say it is nonsense, you cannot do that, but I do critically evaluate his advice. [...] And if I do not agree or have questions, well, then I discuss this with him</i></p> <p>With medication, you often know what will happen. Surgery is often much more radical to me: Then you need stop your medication, you need to be hospitalised, you just feel much worse. [...] If the time comes that a surgery is necessary, then the doctor can make that decision. Not me.</p> <p><i>When starting medication I prefer to share in the decision-making process. Increasing the dosage is something I want to decide myself, as I'm the one who can best determine how severe my pain is. And the doctor decides if the dosage needs to be decreased, because he/she understands what my blood level results mean.</i></p>
EM12 Wiljer, David et al. - 2013	<p>Participants reported feeling comfortable sharing their opinion and discussing aspects of their health condition and trajectory of care with the clinician.</p> <p>Participants were able to reflect on their diagnosis, treatment and strategies for carrying out their goals and were motivated to implement the recommendations given to them by the clinician</p> <p><i>...that encourages me quite a lot to seek out the program and find out more about it</i></p>

Table 4 - Respect

CO01 Sacks, A. Abt et al. - 2016	<p>detailed explanations on diagnostic procedures and treatments</p> <p><i>he gave me the information I wanted to know</i></p> <p>the explanations adapt to each patient's level of understanding</p> <p>professionalism</p> <p><i>kept me informed at all times, telling me what to do or not to do as the treatment progressed</i></p> <p>scientific rigour</p> <p>prestigious institution</p> <p>good reputation</p> <p>incredibly trained team</p>
CO06 Graves, K. et al. - 2011	<p>to recognize the important role cultural beliefs and spiritual practices play in the lives of African American women</p>
CO08 Dowling, Joni E. - 2010	<p>one of the best</p> <p>It seems like all the doctors respected each other's area of expertise.</p> <p>actively seeking patient feedback.</p>
CO09 Laws, M. Barton et al. - 2012	<p>That man will forever be a savior to me</p> <p>maintaining a respectful manner</p> <p>Accuracy in diagnosing</p> <p>Respect/care for patients</p> <p>Knowledge and skills</p> <p>Transparency</p> <p>heightened respect, care, and concern</p> <p>HIV-friendly and treating patients with respect and dignity</p> <p><i>Like they don't care about my health situation [HIV]. It doesn't bother them, and they treat me like any and all patients should be treated. With dignity and respect</i></p> <p><i>they know we see a lot of HIV patients, we're more HIV friendly</i></p> <p><i>she (dentist) really knows what she's doing because I don't feel any pain.</i></p> <p><i>I like to think that I'm gentle with them</i></p> <p>participants felt they had a duty to respect professionals</p> <p><i>If I have an appointment, then of course I must attend or postpone it if I cannot attend</i></p>

EN14 Hirjaba, Marina et al. - 2015	<p>patients' duties were seen as affecting healthcare professionals' workload and commitment to work.</p> <p><i>The health care staff do not need to do extra work, if the patient is honest and trust works both ways.</i></p> <p>Communication</p> <p>safety</p> <p>sincerity</p> <p>trust</p>
EN40 Rise, Marit By et al. - 2013	<p>The respect aspect was described as fundamental for patient and public involvement and included mutual respect and acknowledgement between service users and providers.</p> <p>service providers seeing and hearing the user, viewing the user as a human being and equal party</p> <p>the importance of being listened to and taken seriously</p> <p>to be heard, seen, and valued.</p> <p>Service providers described on the other hand respect as an implied and self-evident value in all treatment practice</p> <p><i>In my opinion the professionalism and the fundamental respect... the attitude... its in our blood</i></p> <p>of being respected and acknowledged during periods of strong symptom</p>
EM11 Nota, Ingrid et al. - 2016	<p>Expertise of the doctor highly but wanted to be a part of the decision-making process</p>
EM12 Wiljer, David et al. - 2013	<p>individually supported because they were</p> <p>able to speak with the clinician</p> <p>considered their time together valuable</p> <p>comfortable sharing their opinion</p> <p>discussing aspects of their health condition and trajectory of care with the clinician.</p> <p>able to reflect on their diagnosis</p> <p>carrying out their goals and were motivated to implement the recommendations</p>

Table 5 - Feeling useful

CO05 Mota, Lorena et al. - 2015	<p>I feel useful in providing care for neglected, underserved [they] need my medical expertise</p> <p>I enjoy the challenge of addressing diseases from around the world</p> <p>important factor for acceptance was feeling useful providing care to migrant patients, which could help create the interest required to better serve this population</p> <p><i>I feel with this particular population the needs are very high and the interventions have huge impact</i></p>
CO06 Graves, K. et al. - 2011	<p>It may provide motivation for them</p>
CO06 Graves, K. et al. - 2011	<p>Having that information...can be very empowering</p>
CO06 Graves, K. et al. - 2011	<p>More genetic counselors and medical oncologists made references to the alleviation of fear and anxiety</p>
CO06 Graves, K. et al. - 2011	<p>additional information about risk can be reassuring</p>
CO10 Burr ridge, Letitia H. et al. - 2011	<p>preoccupation with the cancer patient alters caregivers' frame of reference</p> <p><i>[Carers may feel] we are not really legitimate players in this [but are] here to support our relative</i></p> <p><i>it is important to establish a relationship</i></p>
CO17 Garon, M. - 2012	<p>Doing whats right – we're fighting for our patients</p> <p>here was something internal in them that gave them the courage to speak up. Some reported that they learned this at home, in nursing school or other Staff role modelled these behaviours.</p>

		That's my responsibility to advocate for my patient , against the doctor, against anybody for my patient
CO20 MacDonald, Kath et al. - 2015		HCPs perceived leniency
CO21 Berry, Judith A. - 2009		offers support
EN03 Locock, Louise et al. - 2011		Benefiting those who may go through a similar experience
		Moral duty
		Community spirit
		Furthering medical knowledge for the common good
		for the benefit of significant others , particularly in diseases with genetic risk factors
		<i>One's moral obligations as a human being</i>
		desire to benefit medical science and contribute to scientific knowledge .
EN07 Hout, Marie Claire Van et al. - 2012		<i>I don't mind users and [people in] recovery together – we all tackle it together</i> <i>It's so lonely in early recovery. I'd really feel good to help other people</i>
EN15 Maten- Speksnijder, Ada J. et al. - 2016		the NPs emphasised they possessed empathy ' <i>because they were nurses</i> '.
EN21 Buck, Deborah et al. - 2014		<i>I'm there [in PPI] because I want to change things</i>
EN25 Robinson, Nicola et al. - 2015		Wanting to make a difference , give some- thing back, or a sense of community <i>having patients on my side, or at least trying to drive my agenda from their agenda, gives me more credibility because one, they're the taxpayer (...) they're the guys on the receiving end of the service.</i>
EN28 Safo, Stella et al. - 2016		Reasons for joining the CAB [are, among others] wanting to represent the community [...]
EN33 McDonald, Ruth et al. - 2008		<i>It was lovely to see a smile on their face as soon as they walk in and say "I feel great" or "Feel 100 percent better" and they're actually telling me that, you know (Pause) I've made a difference really.</i>
EN41 Thompson, Jill et al. - 2014		<i>I mean I'm there for their benefit, not for mine. . . . Yeah, I like to think that I'm helping</i>
EN45 Young, C. et al. - 2016		felt a sense of pride in the data they had collected provide personalised health information to clients.
ED5 Albarran, Cynthia R. et al. - 2014		A few women even volunteered to be future promotoras and one wanted to host the programme at her church
ED7 Hurt, Tera R. et al. - 2015		It affects you being the head of your family . Your family looks to you
ED8 Sekse, Ragnhild Johanne Tveit et al. - 2014		[I] feel that I can contribute with my experiences . I had no idea that I would learn so much. When I was asked to participate, I thought maybe we would be helping someone who came after us , not that we ourselves would receive help
ED10 Costello, Joanne F. - 2013		...role is a facilitator's perceived professional "way of being" in relation to the support group
ED11 Dale, Jeremy et al. - 2008		valued the positive feedback from patients and the improvements that were reported to have occurred as a result of the telephone support. What did you enjoy most about participating in the study?

	- Satisfaction with helping other people <i>It's hugely satisfying when you've got somebody on the end of the phone, who's...the sort of third time that you've telephoned them, and she tells you that she's losing weight and she's achieving what she's setting out to achieve.</i>
ED16 Wright, Nicola - 2013	I got out of it most was helping other people , helping other people who hadn't had their illnesses as long as I had and were still coming to terms with it
EM05 Oliffe, John L. et al. - 2008	Group 6 had a 10-point charter that listed the group's aims [...] Points 7, 8, and 9 addressed broader issues including a commitment to prostate cancer advocacy, research, and raising public awareness Many men also wore pins and wrist bands to signify their prostate cancer survivor status . For example, reef knot pins (designed by the Vancouver Island Prostate Cancer Research Foundation in 2002), symbolizing strength, unity, and courage , became the national symbol of PCSGs, and blue prostate cancer wristbands with the same motto were commonplace at the meetings
EM10 Peterson, Jennifer L. et al. - 2012	<i>Typically one of the research nurses would call and let me know that a patient was coming in that was newly diagnosed and wanted to talk with someone. I would come here and spend an hour, even more talking with that person, more listening to them than talking.</i> <i>I would like to think that I served as an example to folks who were newly diagnosed in terms of how one can live and manage the disease in a healthy way.</i> Providing support to others has been shown to be therapeutic in other contexts <i>I try to get them to understand that we have it, it's here and we have to face it. I try not to look at what it can do; I look [at] what I can do to overcome that. I try to share that. Some participants discussed relying heavily on friends who had HIV infection as peers.</i> <i>Things I wish people would have did but, even washing dishes.</i>

Barriers in patients and providers communication

Table 6 - Lack of communication, harsh

CO01 Sacks, A. Abt et al. - 2016	each specialist was focused on their area of intervention, in their 'field', and not on the patient as a whole <i>Cancer is a terrible word</i> <i>I think they are too straightforward, they don't know how to communicate this kind of thing don't think they are prepared for that</i> <i>They are practically telling you are going to die, I don't know, it needs to be a little gentler, quieter, a little more...gradual</i> <i>everything sounded bad, everything looked gloomy, or maybe they made it look that way, I don't know</i> <i>It's not what they tell you, but how they tell it to you and in my case it was very brutal without a warning</i> <i>He even told me that there was the chance he might have to castrate me</i>
CO02 Dellasega, Cheryl et al. - 2011	negative feedback (guilt provoking, nagging, shaming) from both family and health care providers to coerce them into taking responsibility for their diabetes humiliating relationships with physicians felt paternalistic and rushed <i>The doctor is going to give me hell about something.</i> <i>You can't ask a doctor. I mean you could, but they don't understand, and they don't have the time</i> <i>no one is listening to you</i> stressful agitated don't want to deal with

CO04 Sarah Delea, et al. - 2015	two participants explained that they were left in "shock" by the blunt and direct manner in which their surgeon informed them of their imminent amputation <i>I'm going to take your leg off...He just frightened the life out of me</i> He didn't even introduce himself at all
CO06 Graves, K. et al. - 2011	physicians tend to be less likely to refer [African American patients] for more expensive procedures [and] testing than White patients <i>these cultural beliefs tend to be dismissed</i> <i>overlooked</i> African American providers expressed concern that other physicians may not discuss genetic counseling and testing in a culturally appropriate way , thus potentially contributing to lower use among this group [there may be a] disconnect to how information is presented
CO07 Alexander, Stewart C. et al. - 2012	(19%) did not address either issue or did so only with hedging .
CO08 Dowling, Joni E. - 2010	<i>Kind of moved really fast, which is not what I hear from a lot of other women</i> <i>My gut feeling is this is nothing</i> <i>...it's big, blah, blah, blah. It's not attached to anything</i> Her physician told YWWBC6 she was a cancer phobia and a hypochondria <i>wasn't hearing her.</i> <i>felt angry.</i> <i>easy to get caught up in something that is completely unrelated to you.</i> the medical field did not consider the mental aspects of the disease
CO09 Laws, M. Barton et al. - 2012	<i>get intimidated by your doctor</i> hurried visits confrontational and directive style <i>she didn't know how to actually express those feelings in a professional manner</i> <i>She's calling him avoidant and that's a bit offensive.</i> physician's tactic of accusing physicians' failure to ask open questions understand what was really happening with the patients <i>I might get offensive</i> <i>I noticed many of the monologues of this doctor, they ended with these multiple questions that I personally would not be able to answer. I would feel confused</i>
CO10 Burrige, Letitia H. et al. - 2011	GPs may not recognise the retracted or demanding nature of caregiving or its potential toll on caregivers as patient One admitted his preference " to deal with [issues] as they come up <i>if the GP doesn't facilitate it, people won't bring it up</i> <i>too rushed to be able to talk to people in detail</i> some caregivers reported that their regular GP was unreceptive
CO11 Meyer, Samantha B. et al. - 2012	<i>ah it's nothing—you'll be alright'.</i> insufficient provider information provision patients are not receiving the anticipated information, burdening them with the need to ask increased questions the use of causal language can be seen as potentially deemphasizing the patient's role
CO19 Brez, Sharon et al. - 2009	Complex patients were generally described in two ways, those who had " difficult " temperaments or who were " non-compliant " with therapy potential disagreement included incompatible understandings of blood glucose targets , diabetes self-management behaviors, or responsibility for treatment decision-making
CO20 MacDonald, Kath et al. - 2015	repetitive time consuming boring exhausting

		<p><i>Retelling the same stories several times to each of the HCPs.</i></p> <p><i>you're stuck in a room, been questioned</i></p> <p><i>Think they're bullet proof at this stage</i></p> <p><i>they just want you to focus on your CF, and that's all they see</i></p> <p><i>they're just filling out forms,</i></p> <p><i>it's a pain</i></p> <p>Clinic is tick boxes; medically orientated,</p> <p>repetitive</p> <p>communication doesn't get passed on</p> <p>perceived ritualised and repetitive clinic model</p> <p>ceremonial order</p> <p>constant checking of adherence to treatment</p> <p><i>Should we trust them to take their medicine? No we shouldn't trust</i></p>
CO21	Berry, Judith A. - 2009	<p>NP disagrees, confronts, shows antagonism</p> <p>It looks like you have gained weight</p> <p>shows tension</p>
CO23	Davies, Jane et al. - 2014	<p>[the consultation left them] like the clinic staff were purposely hiding something from them</p> <p>worried</p> <p>angry</p> <p>frustrated</p> <p><i>I figured there was something wrong with me when they kept on requesting more and more bloods from me</i></p> <p><i>Sometimes doctors hide something to the patient and they don't want to tell straight</i></p> <p><i>She's saying, she doesn't understand, it's not much meaningful</i></p> <p>Culturally important relationships between certain individuals, which health care providers may not be aware of, were seen as a barrier to effective communication.</p> <p>non-Indigenous key informants reported that an analogy with hepatitis B using a local animal (e.g. a crocodile or snake) to represent how the virus can lie dormant in the liver and then suddenly attack resulting in serious health consequences would be culturally appropriate. By contrast, Indigenous participants generally preferred more medical imagery requesting to see a real human-like figure with a real liver, and a story based in a culturally appropriate setting</p>
CO27	Dolce, Maria C. - 2011	<p>failed expectations related to evidence-based practice, clinical expertise, informational support, and therapeutic interpersonal communication.</p> <p>Survivors presenting with rare cancers or unusual side effects encountered healthcare providers with a lack of clinical expertise in treating their disease</p> <p>perplexed about their healthcare provider either not knowing or withholding important information.</p> <p><i>is not a good communicator</i></p> <p>have less and less time to really communicate with patients</p> <p>some healthcare providers who were unwilling to discuss health information found on the Internet.</p> <p><i>Having researched and learned a great deal about my specific cancer, I find that most doctors would rather the ignorant patient</i></p> <p>perceived healthcare providers as "unconcerned" about their symptoms and consequently turned to the Internet</p>
CO29	Reimann, Swantje et al. - 2010	<p>rude</p> <p>arrogant</p> <p>feel rushed</p> <p><i>you have to repeat your case history every time</i></p>
CO36	Wilkinson, Emma et al. - 2014	<p>A small number reported their satisfaction with the quality of the care they had received to date</p> <p>dissatisfaction</p> <p>a bad, unapproachable attitude.</p> <p>the GP was great around diagnosis but of late has not been so supportive</p>

	<p>hard to speak to him</p> <p>Doctors just see you as one of many, do not cater for individuals</p> <p>I don't feel they support you as such</p> <p>they just follow protocol</p> <p>a standard procedure they go through.</p> <p>They give you leaflets and stuff but it is up to you to read, they are not concerned if you do or not</p> <p>the GP just checks me out and does the routine stuff but does not give me any encouragement nor does he understand what I am going through</p>
EN01 Ekundayo, Olugbemiga T. et al. - 2012	<p>unfriendly</p> <p>disrespectful</p>
EN04 Cook, Catherine - 2012	<p>She didn't have any idea of the impact on me and I kept my tears until outside</p> <p>problematic encounters with clinicians that compounded feelings of loss of control</p>
EN05 Graffigna, Guendalina et al. - 2014	<p>Information given from the doctor to the patient often appears partial.</p> <p>Educational and informative supports are often ineffective</p> <p>The patient tends to "escape" the encounter with the doctor,</p> <p>Poorly attuned to patient needs and priorities</p> <p>he doctor-patient relationship sometimes appears challenging and patients tend to avoid contact</p> <p>I hate the controls</p> <p><i>Sometimes I ignore the appointments and I don't go</i></p> <p>I don't feel very supported by my doctor. I do not feel like I could express my feelings, my difficulties</p>
EN06 Walters, Chasity Burrows - 2013	<p>incongruence between the body language and the verbal messages delivered by their HCPs</p> <p>feeling rushed</p> <p><i>Not everybody is a good communicator all the time, especially when you're not feeling good.</i></p> <p>I feel like, oh yeah, right, I'm going to be telling medical people what to do.</p>
EN09 Flournoy, Minnjuan W. - 2011	<p>Poor attitude</p> <p>Unfriendly</p> <p>Patients expressed their discontent for the attitude of a particular provider, and discussed how they had actually decided to not return to scheduled appointment</p> <p>how it even had a negative impact on the work environment.</p> <p><i>His attitude was the worst. And everybody could tell having the dentist that was a jerk...</i></p> <p>rude and unfriendly</p> <p>Uninviting gestures such as rolling of the eyes, scoffing, and shaking the head in a disapproving way</p> <p>no customer service skills whatsoever.</p> <p>He never smiled, never greeted me, nothing, kinda cold and not warm or welcoming</p> <p>I expect the person who's gonna drill a hole in my head to at least speak to me</p>
EN10 Brooks, Fiona - 2008	<p>The patients' council wouldn't necessarily know what needs doing over the next 5, 10 years, but I do.</p> <p>When they started coming up with their own ideas I thought, 'there isn't time for all this; this is what I want them to do'</p> <p>Negative reactions from nurses were most notable when the patient councilors' attempted to raise their personal experiences of care as a means to suggest an issue for the agenda</p> <p>Narratives or 'story telling' about experiences of care were felt by nursing staff on the committee to be unnecessary subjective interruptions</p> <p>an empowered questioning group of patients was particularly challenging for nurses.</p> <p>you didn't want personal involvement, but that's all we can offer you really, is personal involvement and feedback from other patients</p>

EN14 Hirjaba, Marina et al. - 2015	Discouraging and accusing the patient was perceived to have a significant negative impact on their morale and led them to ignore their duties and decrease their commitment to self-care .
EN15 Maten- Speksnijder, Ada J. et al. - 2016	checking the EPR constantly, The consulta- tions were mostly based on a conventional medical model of medical history taking someone's health condition can be fully accounted for by deviations from normal biological function Little attention was paid to the social, psychological and behavioural dimensions of illness. constant use of the EPR Some NPs stopped talking while making electronic notes . Others switched to a lighter topic they lost eye contact with the patient. While making her notes, she tries not to lose contact with her patient by asking the girl about school. But the girl did not seem very keen on answering this question . NPs rarely addressed the emotional aspect 'How are you?' the NP asks. Alice answers: "Bad, I had a lot of pain last week", and she hands over a piece of paper. The NP does not pay much attention One NP held 30-minute clinics and took time to report in the EPR after the patient had left. During the consultations most NPs were checking the EPR constantly
EN18 Mitchell- Brown, Fay et al. - 2017	<i>if they wanted us to get better, then maybe they would have provided us some education about diabetes. Because they don't, we always go in for visits to get medications. It's a way for them to get money from us.</i> some participants expressed belief that doctors took advantage of Hmong individuals who have no insurance coverage and use them as test subjects
EN24 Powell, Rhea E. et al. - 2016	<i>The doctor is just focusing on my medical needs and not focusing on my life issues or... looking at me as a human being.</i>
EN32 Hogden, Anne et al. - 2012	<i>I try to pace myself, not to give them all the information from the beginning of the disease until the end of life, right in the first session.</i>
EN33 McDonald, Ruth et al. - 2008	<i>"I eat like a bird. I honestly eat like a bird". Well if you're eating like a bird, what type of bird are we looking at? An emu?</i> [NPs] challenging the validity of patient views [NPs] painted stark pictures intended to shock
EN36 CLOCHESY, JOHN M. et al. - 2015	<i>She never knew, because I work, you know carry out my life as life should be. Well for a year and a half I was treated just like I was supposed to be treated, like a human being. Well someone sent a letter back... I come to the doctor for my next visit and she was like, she went from being a nice person to 'Well you're homeless. I don't want to be your doctor anymore,' and I said 'Excuse me?' I says, 'What does that have anything to do with?'... Well she never treated me the same way as she did after she found out that I wasn't staying in my own place treated differently <i>That's right, it's there, ... I have went to doctors and told them, I'm in pain,' just like you. Look at me and literally tell me almost, 'Okay, I can't give you no drug to get high off of.' I'm not coming in here for this. I'm in pain [AA women, lupus] they still talk to me like I had shit smeared on my face, you know It is totally ridiculous. I would never recommend that hospital to anyone to go to it, you know because they is just totally ridiculous, period. As soon as you walk through the door, you know you just feel the vibes, turn around and go back out, you know, 'You ain't gon' get no help here.' the second question he asked me was I gay, and when I said yes he said he would not treat me and told me to leave</i></i>

		<i>you're no longer treated as a human being. You're treated either as some sort of fascinating test rat</i>
		<i>I understand you're practicing medicine, but don't practice on me, and 'Let's try this aspirin, and let's try this and let's try that.' 'Hold on, man. I listen to the commercial too</i>
EN38 Fiona et al. - 2014	Ross,	<i>Professionals who are offhand and who do not want to listen to your view</i> <i>Professionals who do not respect you or your property</i>
EN38 Fiona et al. - 2014	Ross,	<u>Service users' views of less good care</u> <u>Mental health conditions</u>
EN38 Fiona et al. - 2014	Ross,	<ul style="list-style-type: none"> • (Service users' views of less good care • Communication: information and explanation • Conflicting advice from different professionals • Ways in which professionals behave • 'Every health problem is seen as part of my mental health problem: I am exasperated!' • Not being taken seriously; feeling stigmatised; and a 'burden' • Assumptions that medication is the be-all and end-all • Access to services • Access to services limited by attitude, e.g. gatekeeping; • availability, e.g. shortage of social workers; rationing of • services, e.g. reductions in access to emergency care • Having to be in crisis before access to services is granted • Continuity • No one is monitoring the overall picture • A high turnover of CPNs
		<u>Physical health conditions</u>
		<ul style="list-style-type: none"> • Communication: information and explanation • Not understanding the system, e.g. community matron 'doesn't understand her purpose' • Lack of explanation leads to feeling blocked by the system, e.g. 'can't do this because of that' • Ways in which professionals behave • Professionals who are offhand and who do not want to listen to your view • 'Professionals who do not respect you or your property' • Access to services • Problems making General Practitioner appointments • Rehabilitation services stopped certainly after the allocated • 6-week period irrespective of further need • Individualised, flexible and responsive care • 'Little things get forgotten'
EM01 Hanne et al. - 2015	Agerskov,	<i>the donor's answer seems elusive and was, apparently, as not heard, the doctor did not seek further elaboration of, or reply to, the donor's response</i> <i>how a sense of vulnerability and powerlessness became evident in relation to not being able to back out of the situation.</i> <i>when communication and the agenda are not clear, the donor can experience subsequent actions by the healthcare staff as overstepping the mark</i> <i>[the]donor could react by protecting herself and either adopting more dismissive behaviour</i> <i>[the donor] could decide to refrain from donation.</i>
EM04 Linda et al. - 2013	Boise,	<i>Some of the diseases that we have over there are not the same, and they [doctors] are deducing from what he thinks rather than what you are telling him</i> <i>the doctor needs to take the time to review, make sure communication is clear, but that doesn't often happen.</i>

	Lack of cultural understanding [Lack of] sensitivity you are considered not to have money, you are considered not to understand
EM06 Phillips, Janice et al. - 2011	He pulled out the freaking algorithm and showed a flow chart
EM07 Bhattacharya, Gauri - 2012	this disconnect between the T2D self-management guidelines and the realities of their lives women participants to experience their doctors as “disrespectful.” These questions make me feel uncomfortable!
EM08 NANTON, V. et al. - 2011	he didn't come with any diplomatic way of saying it Brusque Insensitive It hurt but that's the way it is
EM11 Nota, Ingrid et al. - 2016	Doctor does not listen/take patient seriously “I told him: ‘I am very tired, though.’ And he said: ‘Yes, half the Dutch population is tired.’ Doctor does not recognise role of patient Offers no alternatives “If you do not agree, you say so. But if he then explains it and there are no alternatives, well, then there is nothing to choose.” Immediately rejects the patient's questions or suggestion
EM17 DiGiacomo, M. et al. - 2015	Loss of voice disempowerment in communication and interactions with health professionals doctors attributing presentations to mental health issues Labelling and stigma misconceptions of English language mastery. Anglo-dominated world views and language, education level time restrictions and comorbidities Dismissal Community participants described their perception that doctors are disbelieving or dismissive of their health complaints, particularly in the case of chronic conditions to be believed is one of the biggest problems... do not appraise their complaints as requiring investigation. Yeah, but when you go and see a professional person, and you come out of it feeling like you shouldn't have gone, something's wrong <i>their local doctors and how they didn't listen to them, that's a major one.</i> <i>they just pushed them off as long as they got them out of the place in five minutes</i> avoidance strategy

Table 7 - Paternalistic communication

CO02 Dellasega, Cheryl et al. - 2011	negative feedback (guilt provoking) treated like a child And as an adult you want to be treated as an adult
CO08 Dowling, Joni E. - 2010	they advised me not to go on the Internet because of getting overwhelmed with information
CO09 Laws, M. Barton et al. - 2012	She's seeing that fact in the history that he's going down below 200 and the doctor getting upset about that is very, very understandable. They're in this business to save lives, not lose lives. . . . I don't think she was rude, I think she was giving him tough lo
CO09 Laws, M. Barton et al. - 2012	she's talking like to that client like if she's talking to her kid – the tone of her voice and what she was saying to him. She basically wanted to give him tough love, but she didn't know how she was informative, but I felt like she kept going on going back and around in circles, and like she was trying to get a reaction out of the patient.

CO20 MacDonald, Kath et al. - 2015	Attitudinal barriers: [attributes & beliefs,e.g. power, trust , respect , knowledge of young people (YP)] HCPs were more sceptical about the term suggesting that there were many patients who perceived themselves to be an expert who were not
CO27 Dolce, Maria C. - 2011	<i>Our local oncologist did not want to discuss them with me, but the experts we saw were using these very articles to make their decisions about treatment recommendations.</i>
EN23 Davies, Freya et al. - 2014	only patients who could understand the correct use of self-treatment should be offered rescue pack
EN32 Hogden, Anne et al. - 2012	concerned about the ability of the patient to discern between credible websites and those promoting false hopes of cures and treatments. Clinicians reported a sense of responsibility to monitor the quality of information accessed by patients , and to provide guidance on the range of evidence-based information available
EN33 McDonald, Ruth et al. - 2008	d a relationship of dependency which at times resembled, if not master and slave, then mother and child , rather than a meeting of equals <i>We give them a blood test so then we can show them where they have come from and where they're going, so that it's a ... it's a continual rewarding system ... you know whenever they come back we give them a blood test, we give them the results to say "good boy you're doing really well"</i> Nurses identified " good " and " bad " patients, with such categories doing moral work, patients depicted as a tabula rasa on which nurses could inscribe good behaviours, chimes with the idea of patients as children <i>you're saying "Well I'm too old" ... you're contradicting yourself aren't you? ... you'll get more onto the "get tough syndrome" of, you know, "Look if you, if you don't do something about this, then you're shortening your lifespan by ten years", and then, "I mean do you want to do that? Do you not want to see your grandchildren"</i> you've drunk ten pints a night, ten pints of beer a night for a week, you're abusing me nurses felt frustrated and abused by patients who failed to act as compliant or contrite and refused to bow to the "superior" wisdom of the nurses involved in their care
EN38 Ross, Fiona et al. - 2014	<i>Every health problem is seen as part of my mental health problem: I am exasperated!</i> Not being taken seriously ; feeling stigmatised ; and a 'burden'
EN40 Rise, Marit By et al. - 2013	<i>To be able to tell what you want. That your wishes are being heard. That the providers dont make a plan that pacifies you...Pacified... I feel its to be managed, to be overruled</i>
EM04 Boise, Linda et al. - 2013	They talk so fast to you or they talk to you like you are a baby . It's so annoying!
EM06 Phillips, Janice et al. - 2011	Participants expressed concern that providers thought they were too young to have breast cancer. Even for those seeking care for abnormal breast findings, their concerns were not always met with appropriate attention . One participant commented on the watchful waiting recommended for young women with breast symptoms
EM08 NANTON, V. et al. - 2011	Some men had been told by their doctors that they should not expect to be sexually active at their age.
EM17 DiGiacomo, M. et al. - 2015	older generations may feel that the ' doctor knows best ' and accept his or her word without question . Depending on the doctor-patient rapport and individual characteristics and skills , women may not feel confident to ask questions during consultation
EN10 Brooks, Fiona - 2008	<i>The patients' council wouldn't necessarily know what needs doing over the next 5, 10 years, but I do.</i>

Table 8 - Insufficient information; lack of information; discontent with the info received

CO01 Sacks, A. Abt et al. - 2016	they reported that the initial information was not conveyed clearly, leading to doubts. Follow-up during the treatments and recommendations related to self-care, prevention of complications, healthy habits or preventive activities
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	<p>psychological impact</p> <p>follow-up and post-treatment monitoring</p> <p>relapse, side effects</p> <p>frequency of post-treatment</p> <p>ambiguity reinforced feelings of uncertainty.</p> <p>insufficient</p> <p><i>I wasn't completely informed on all of the side effects</i></p> <p><i>They gave me little information</i></p> <p><i>he did not explain in depth</i></p> <p><i>nor mentioned anything about rehabilitation, physiotherapy... in my hospital there was no physiotherapist, nothing even remotely similar, so there was also very little information</i></p> <p>partial information</p> <p>without consensus</p> <p>Little consensus among the different professionals</p> <p><i>I also like to have a lot of information, so well, if you don't give it to me, I'll look for it somewhere else, or I'll ask about it. This is reason why I am in the association.</i></p> <p>being in a hurry when delivering information, little or no time to ask questions</p>
CO02 Dellasega, Cheryl et al. - 2011	<p>physicians were unable to listen to them or engage in a dialogue due to time constraints</p>
CO04 Delea, Sarah et al. - 2015	<p><i>Nothing was explained to me properly...</i></p> <p><i>I didn't get the proper information- what could happen</i></p> <p>all of the participants reported receiving education and information regarding their illness, some indicated that they were not aware of foot problems pertaining to diabetes until they were treated for a foot ulcer</p>
CO06 Graves, K. et al. - 2011	<p><i>Some primary care docs may know about it, but [it is] unlikely</i></p>
CO07 Alexander, Stewart C. et al. - 2012	<p>in 5% of consultations; quantitative prognostic information about mortality was presented but always with hedging</p> <p>In 22% of consultations, mortality was not discussed using numbers or not discussed at all</p> <p>When palliation discussions did come up, they were often discussed as an option if other treatments failed and thus were often discussed very briefly and vaguely.</p> <p>It was rare for patients and physicians to discuss what role patients could play in recovery</p>
CO08 Dowling, Joni E. - 2010	<p><i>I had trouble getting a follow-up appointment</i></p> <p>The doctor told YWWBC4 not to worry about it because she was too young</p> <p>was probably nothing since she had no family history,</p> <p>Her practitioner did not want to do a mammogram and expose her to radiation</p> <p>He discounted it and didn't really think it was anything but he had her go for a mammogram.</p> <p>nothing was registering</p> <p>odd experience.</p> <p><i>They did a biopsy. I didn't hear anything, so I called</i></p> <p>needed more information about side effects</p> <p>needed more information on</p> <p>preserving fertility and long-term effects of treatment</p> <p>She found the lack of information to be frustrating because physicians asked patients to make massive decisions about their bodies, and the "two huge areas of medicine [cancer and fertility] are full of unknowns</p>
CO09 Laws, M. Barton et al. - 2012	<p>patients failing to get their agendas addressed on occasion.</p> <p><i>I think a doctor should . . . be more professional, let you know what the side effects are</i></p>
CO10 Burridge, Letitia H. et al. - 2011	<p>his GP "is only interested in the [cancer] patient"</p> <p>the initiative remains the prerogative of the caregiving patient</p> <p>a caregiver who does not ask needs no help.</p>

CO11	Meyer, Samantha B. et al. - 2012	<i>I don't just want a GP that takes your Medicare card, writes you a script and wants to get patients in and out</i>
CO12	Rubio-Rico, Lourdes et al. - 2014	[...]some professionals encourage the presence of minors in appointments without considering ethical issues relating to the rights of the child or the quality of care provided under these circumstances the quality of the translation that a child can offer: <i>"Yes, [professionals] don't want children Translations are of poor quality</i> Ignorance of the terminology involved in the doctor's appointment makes translation difficult e refusal of the child to translate certain subjects issues may even lead to an absence of translation: <i>"The doctor's message changes. Yes, because they're embarrassed</i> says that perhaps a small child cannot
CO13	Venetis, Maria K. et al. - 2018	contemporary guidelines that urge providers to "limit the amount of information provided"
CO14	Hersch, Jolyn et al. - 2013	The idea of overdiagnosis occurring in breast cancer screening was surprising and challenged women's beliefs in the statistics, but we don't hear about it, not even from our doctors surprise or disbelief at the current limitations we described in distinguishing between cancers that do require treatment and those that may not. <i>they would be able to tell you whether they are aggressive or not, right?</i>
CO15	Hart, Ruth I. et al. - 2017	fatigue-related communication with health professionals (in primary or specialist care) appeared limited barriers specific to fatigue. These include: reliance on a colloquial vocabulary ("so tired", "exhausted", "knackered", "wiped out", "done in"); uncertainty about fatigue's relationship to rheumatic disease; doubt as to fatigue's 'place' on the consultation agenda; and a belief that nothing can be done
CO19	Brez, Sharon et al. - 2009	Insufficient time to adequately address diabetes care <i>I know that I should really give more time to that patient</i> <i>I need to feel good about myself as a doctor and not to give the time needed to that patient really gives me part of my daily frustration</i> gaps in their own knowledge and confidence related to current treatment of diabetes
CO20	MacDonald, Kath et al. - 2015	<i>everybody asks the same questions, goes over the same things and you just feel like you're repeating yourself a lot</i> HCPs' admissions of being too soft in the consultation, the amount of rule-bending in this context might not be tolerated in other client groups
CO22	Smith, Sian K. et al. - 2008	several of the higher literacy participants found the new version dumbed down there is a risk of some people feeling like their intelligence is being insulted misinterpretation led them to overestimate the likely benefits of screening. When the same information was expressed as absolute risk data, using graphical formats (e.g. smiley faces /systematic oval diagrams), both literacy groups were surprised that the figures did not produce a more compelling argument in favour of screening There was variation in feedback about the use of smiley faces and systematic ovals. Higher literacy participants generally felt that the faces were suitable for a younger age group. In contrast, most of the lower literacy participants were indifferent towards the faces but found them difficult to interpret design may not be culturally appropriate
CO23	Davies, Jane et al. - 2014	distinct lack of biomedical knowledge they did not know or have any understanding of what hepatitis B were commonly unable to attempt any explanation on direct questioning . Aboriginal health workers (AHW) and this appeared to be the origin of knowledge for this group, as similar concepts and responses were reported. The concepts of mother to child transmission, sexual acquisition and the ineffectiveness of blood and other body fluids were expressed by several AHWs; however they were less clear about the natural history of the disease, the interpretation or meaning of blood test results, and the potential for treatment or intervention.

	<p>lack of continuity of care.</p> <p>they were asked to have many blood tests related to their diagnosis of CHB, without receiving adequate explanation of their purpose,</p> <p>there was a lack of follow up to receive and discuss the results</p> <p>lack of understanding and communication</p> <p><i>The words are big words, the numbers are not good, and the words are not good. Should be in language</i></p>
CO27 Dolce, Maria C. - 2011	<p>diagnostic failures in which symptoms had been undiagnosed, incorrectly diagnosed, or dismissed by their healthcare provider.</p> <p>Failed expectation: evidence- based practice</p> <p>Having been through treatments by doctors who were not up on the latest tests and treatments</p> <p><i>wasn't getting the correct information from my oncologist</i></p> <p>Not the most rigorous or up-to-date approach</p> <p>lack of informational support from healthcare providers</p> <p><i>"I knew only the little that my urologist told me</i></p>
CO31 Zulman, Donna M. et al. - 2015	<p><i>Most doctors in my opinion don't know the side effects of drugs or their interactions</i></p>
CO36 Wilkinson, Emma et al. - 2014	<p>44.7%) of people reported having information needs</p> <p><i>I have never been told anything about the things that I have said</i></p> <p><i>an idea of what sort of symptoms I can expect over the years</i></p> <p>'They don't really tell you what would happen</p>
CO37 Taylor, Elizabeth et al. - 2014	<p>differing cultural paradigm.</p>
CO38 Duineveld, Laura A. M. et al. - 2016	<p><i>I wonder what the effort of a surgeon looks like. I mean, the patient visits the surgeon at the outpatient clinic and the surgeon asks: "How are you?" "I'm doing fine". "The result of the blood test was good, the ultrasound was normal". At last, he examines the abdomen, they shake hands and that is that. I don't think much of it.</i></p> <p>Lack of trust of patients in expertise of GP</p>
EN01 Ekundayo, Olugbemiga T. et al. - 2012	<p>unclear messages (incomprehension)</p> <p>Cannot understand the term</p> <p>Lack of proper explanation</p>
EN05 Graffigna, Guendalina et al. - 2014	<p>doubts</p> <p>held superficial knowledge related to their health</p> <p>lack of knowledge</p> <p>[lack of knowledge in] "domains of experience", which are crucial – in the subjective representation of the patient – for the daily management of their disease: diet, physical activity and pharmaceutical treatment.</p> <p>doctors would often give "abstract" rules related to their treatment and lifestyle changes, which they had trouble integrating into their daily life.</p> <p><i>The doctor told me that I have to do some physical activity, but he didn't advise on the kind of exercises</i></p> <p>not aware of the inadequacy of their behavior</p> <p><i>I normally engage in physical activity, since I walk to do my grocery shopping, for about 10 minutes a day</i></p> <p>understanding the rationale of the diet regimens</p> <p>The patient reports an abstract knowledge of the therapeutic regime that he/she has to follow</p> <p>patient reports a fragmented knowledge about his/her status and the rationale behind the doctor's requirements.</p> <p><i>I would need more concrete examples</i></p> <p><i>My doctor is good, but he doesn't actually have time for engaging in a real conversation.</i></p> <p>Trust could be broken by negative reactions to their conveyance of information</p>

EN06 Walters, Chasity Burrows - 2013	<i>At first I didn't think I would feel comfortable [saying something about a safety concern], but why not? If it's for everybody's best interest</i>
EN15 Maten- Speksnijder, Ada J. et al. - 2016	The NP does not pay much attention
EN18 Mitchell- Brown, Fay et al. - 2017	<i>I do wonder why is it that when we lived in Laos, our elders never had this disease, b</i> <i>They say that those who are overweight have it (diabetes), but how come some who are overweight don't have it</i> <i>diabetes is a bad disease and I don't know why I have it</i> <i>When you do over-eat, the vitamins in the foods cause diabetes and raise your blood sugar level</i> expected that the medication would totally eliminate the problems of high blood sugar. As this is not the case, the participants poorly complied with their medication regimen. <i>The reason I do not take medications prescribed by the doctor is because some does help you and some may just attack your system and causes other health concerns like kidney failure and blurred vision.</i>
EN20 Pinto, Rogério M. - 2009	lack of training and experience <i>We really needed some additional expertise.</i>
EN21 Buck, Deborah et al. - 2014	challenges (jargon)
EN23 Davies, Freya et al. - 2014	<i>'They do not have enough insight in the disease, they cannot judge the seriousness and then they yo-yo should I do it or wait a day. In short, the doubt.'</i> <i>the consultation time for COPD cases is short, but if we use rescue pack, we have to explain it very clearly and in detail, instead of just prescribe it for the patients. ...I think if we prescribe the rescue pack, we need to assess patients' understanding and then prepare the guidelines for them and it takes time'</i>
EN33 McDonald, Ruth et al. - 2008	They provide a justification for situations in which patient outcomes are not optimal. If such circumstances threaten nurses' identities, then a refusal to accept culpability helps defend against such threats.
EN35 Gien, Lan et al. - 2017	misinformation and outdated advice about food carbohydrate content, frequency of eating meals, and foods to be avoided <i>"...the only diet (allowed) would be fruits and vegetables", "don't eat starchy foods", "fruits are out if you're a diabetic; they're not healthy anymore", "fresh fruit is a lot of sugar... Bananas is probably one of the worst ones that you could eat", "you have to eat five or six times a day".</i> These information gaps indicate that updated knowledge about meal planning for DM has not reached all members of the focus group, perhaps due to a lack of access to health care information or receiving information that was outdated They noted that the advised targeted level is different for each person, such as "I was told 7 and 11 (mmol/L)" or "My doctor don't recommend over 6". A participant added "now the diabetic association says that they accept a 10". It is not known if they understood that this difference is expected as targeted ranges for blood glucose vary depending on a person's age, medical condition, testing time in relation to food intake and other risk factors participants did not have adequate knowledge of DM and how it affected the body frustrations in finding credible information about DM and in accessing health professionals to clarify their understanding. <i>...everyday they're coming out with something, one time they said coffee is no good to you now they says three cups of coffee a day is good for you. The same one time chocolate was no good to you then all of a sudden they say oh dark chocolate is no good for you and then they said eggs is no good for you and then they said eggs are good for you. So...what are you supposed to eat?</i>

		<p>inadequate information, mixed information and even no information about DM from their health care providers, due in part, to the latter's busy practice.</p> <p><i>He (the doctor) told me the sugar was high, put me on medication, no pamphlets, no nothing ...to tell you what to do it's just take these pills",</i></p> <p>doctors' disagreement on DM diagnosis further heightened patients' feeling of vulnerability</p> <p><i>I've had two different doctors, one called me a pre-diabetic and said I didn't need medication and another one says you are a diabetic</i></p>
EN36	CLOCHESY, JOHN M. et al. - 2015	<p>rushed along, not listening to the patient.</p> <p>when the doctor does come in there, it's this rushing in and out business</p> <p>I usually do when I am going for a first appointment with a brand new physician <i>who doesn't know me, I usually take in a two-page typewritten letter which gives my medical history and all the medications that I'm currently on. This doctor looked at very quickly, didn't really read it.</i></p> <p><i>And then the worst of all then, like I said is doctors pushing pills and sending you bills instead of getting to the cause of what is causing the symptoms. The symptoms are signs of that something's wrong. It's like a red light engine light coming on in your vehicle.</i></p>
EN38	Ross, Fiona et al. - 2014	<p>Not understanding the system, e.g. community matron 'doesn't understand her purpose'</p> <p>Lack of explanation leads to feeling blocked by the system, e.g. 'can't do this because of that'</p>
EN39	Durme, Thérèse Van et al. - 2014	<p>(Patients and informal caregivers' association, 2nd focus group) <i>"If we hope that a patient decides for his/herself, we have to be sure that he/she understands the options. We should enable him/her to meet his/her peers, and we should provide information about support groups. This is not systematically offered by professionals."</i></p> <p>(3) information is not well-organized and is obsolete. As a result, patients (a) miss information and therefore lack access to tools to make informed choices</p> <p>It often happens that, in cancer patients, communication with health care providers is difficult. Informal caregivers do not find their place</p>
ED8	Sekse, Ragnhild Johanne Tveit et al. - 2014	<p>While some women had received adequate information throughout the treatment trajectory, others reported having received very little information about cancer and its onsequences.</p> <p><i>Initially I knew nothing... only that cancer was scary...</i></p> <p>One such issue was sexuality and relationships. It's because you don't get any information before</p> <p><i>you go home... and sex is not really what you're thinking about when you leave the hospital after an operation like that, but of course... when you do come home and normal life begins, for most of us [sex] is also a part of life and... gosh... what have they done in there... Am I allowed to... Can we do it? And I remember I had to call [health personnel] and ask.</i></p>
ED9	Santos-Livengood, Christie A. - 2015	<p>these participants shared that doctors either do not give any information about how to protect themselves against sexually transmitted and associated infections, or definitively state that women cannot contract infections from their female partners</p> <p>participants shared that providers often assume they are heterosexual and offer them heterosexually oriented safer sex advice.</p> <p>shared that upon sharing their sexual orientation or behaviors, providers perceived them to have negligible risk and did not recommend safer sex practices, dismissed concerns regarding desired testing or provided them with incorrect information regarding the need to be tested in the future.</p> <p><i>I didn't need one. And I was insistent and I told her that my female partner had gotten it from her female partner, so I didn't think that that was accurate information and [laughs] I think she said, 'You know, I mean to that I would just respond, really?' The implication was very clear that my female partner had been with a man if she had contracted HPV, which I knew not to be the case. So it was a frustrating experience."</i></p>
ED13	Nunes, Julie A. Wright et al. - 2015	<p><i>Well, I have a nurse that—she don't explain anything. She comes up. She will cutthe machine off if it's out—beeping or whatever. But she [won't] tell you why or what's going on</i></p> <p><i>"My iron levels . . . All I know is I'm getting extra iron . . . They don't say, well, your iron level is so and so. They just tell you that it was low."</i> 59-year-old woma</p>

	Regarding numeric displays on dialysis machines during treatments <i>"I think I have my own ideas about it, but I'm not sure they are correct . . . and I would like for somebody to explain it more in detail than they have."</i> (52-year-old woman)
	<i>"We don't get a computer printout of our iron, stats, or our hematocrit stats. It's just the nurses and the doctors get it and I don't think that's right either. I think that we should be able to get the whole, complete, stats of what all of our—all readings are."</i> (59-year-old woman)
	It has not been explained to me just what the numbers represent. What they mean.
	Barriers to applying numbers in kidney care were led by the perception that medical staff did not take time to explain things. During dialysis, there were often alarms indicating a numeric parameter out of "normal range." Patients wanted to understand the meaning of these alarms, and how to interpret them.
ED14 Vega, Gema et al. - 2014	<i>I haven't been told why it happened, just that I had it. And then, then to take care of yourself, nothing at all, take your pills, and that is it.</i>
EM01 Agerskov, Hanne et al. - 2015	<i>So I thought: what is that all about? They told me everything was so good and fine, and for a man of my age. They said there was only 46 ml left in the bladder and it was really good. Then I thought: what is it all about? I thought, oh no, am I not healthy enough after all? It is my older brother who is going to have this kidney ...</i>
	Confusion and frustration could arise when the healthcare professionals' communication and intentions were insufficient or unstructured.
EM04 Boise, Linda et al. - 2013	Doctors unfamiliar with illnesses affecting Africans <i>We come from a culture where we place the doctor at a very high level . . . so we expect the doctor to know what the problem is.</i>
EM08 NANTON, V. et al. - 2011	their knowledge had been vague . <i>Most of us didn't get information before you got prostate.</i>
	little information regarding prostate cancer, treatment and side effects had been given at the time of diagnosis.
	With regard to side effects of treatment, issues of continence were paramount. Men had not felt prepared for the extent and duration of these problems. Little advice had been offered
	Though men had asked for practical support in terms of incontinence aids following the immediate post-treatment period, their supply had been inadequate or slow to materialise.
	Some men had been told by their doctors that they should not expect to be sexually active at their age
EM11 Nota, Ingrid et al. - 2016	<i>He is very good at his job, but I have to ask him everything, for example when I don't agree with something he says. I really need to drag it out of him</i> <i>Then they start using those difficult words at the hospital and I think: never mind, I don't want to hear it anymore</i> <i>But it [an alternative] has to be out there somewhere and the doctor needs to tell me."</i> Did you ask for an alternative? "No, I did not. And I did not know I could, either. If the doctor says it's effective, then I think: You know best <i>Of course many decisions are made for you, because you yourself cannot... I did not know anything about this when it all started</i>
EM12 Wiljer, David et al. - 2013	Participants expressed the feelings of anguish and distress when they sought out medical attention because they felt that their physicians and healthcare team did not have enough time for them.
EM17 DiGiacomo, M. et al. - 2015	The more chronic the disease, the less...interaction they get. health professionals assume the nomenclature around 'chronic conditions' is relevant and accessible to all. <i>I think the whole idea of chronic health conditions is so Anglo, I'm really sorry to say...</i>

ITC tools and EHR are also considered in light of this code; for instance, the counter intuitive access and interfaces and the suspicion of patients about the reception of their messages by HCPs can be considered (CO32). On the other hand, IT tools would

be useful for covering the "knowledge gaps" that a suboptimal communication of patients with their GPs and all HCPs involved may lead; specifically, websites and online resources (EN04). Also, financial constraints and socio-economic hardships could be related to the use of these kind of resources.

CO32 Greenhalgh, Trisha et al. - 2010	poor ease of use a clunky and counter intuitive access the main concern of participants was the fundamental design of the HealthSpace technology and the mismatch between this and their expectations
	<i>I don't know whether people would use it</i> Some participants considered that their general practitioner "didn't mind" receiving messages from them
EN04 Cook, Catherine - 2012	<i>I found the herpes website to be most informative as the doctor is too expensive just to go to for a chat</i>

Table 9 - Overwhelming information; too much

CO01 Sacks, A. Abt et al. - 2016	there's so much information that your head can't think clearly <i>I answered him that it was the same for me, and that whatever he considered best was fine. He told me it was my decision to make oncologists, provided more information than required and that could be assimilated at each time all at once all on the same day they bombard you with information</i>
CO06 Graves, K. et al. - 2011	individuals who receive their test results are not able to "go back" after learning about genetic risk a lack of desire for the information
CO08 Dowling, Joni E. - 2010	<i>he talked to her as if she were a colleague, not a patient.</i> learned of her diagnosis over the phone and she couldn't understand what the older gentleman was saying.
CO10 Burrige, Letitia H. et al. - 2011	They often feel so overwhelmed by what their [patient] is going through that anything they experience or feel they don't consider is important
CO13 Venetis, Maria K. et al. - 2018	increased question asking is associated with decreased patient outcomes , and namely reduced satisfaction
CO14 Hersch, Jolyn et al. - 2013	Some participants thought that making decisions was more difficult when there was a lot of information to go through, or they lacked confidence in their ability to understand numerical information
CO14 Hersch, Jolyn et al. - 2013	<i>They're going to confuse the people</i>
CO22 Smith, Sian K. et al. - 2008	<i>I probably would look through it and think that's too much</i> too many words I dont understand Those with poorer reading skills described the density of text in the original version as intimidating and frightening Lower literacy participants had difficulties pronouncing and understanding the medical terminology <i>medical words and that, not real good.</i> Even those with better reading skills were unfamiliar with the medical language

CO23 Davies, Jane et al. - 2014	<p>Non-Indigenous individuals in the study (all key informants) tended to significantly overestimate the depth of shared understanding between themselves and Indigenous individuals when discussing CHB</p> <p>too many medical terms and a feeling that they were too detailed in content.</p> <p>excess use of jargon</p> <p>to remove all medical jargon and acronyms and translate the simple English into Yolŋu matha</p>
CO31 Zulman, Donna M. et al. - 2015	<p>High volume of records</p> <p>Records from multiple health care systems</p> <p>Long and complicated medication regimens</p> <p>Patient may be the only person who is aware of all medications at any given time</p> <p>Many self-management tasks</p> <p>Patients frequently must schedule and remember a high volume of clinic, laboratory, and procedure appointments across multiple health care systems</p> <p>High volume of appointments</p> <p>Caregivers may be overwhelmed by the number and complexity of health conditions</p> <p><i>I feel like I'm the one who has to coordinate and has to be aware of what's happening.</i></p> <p><i>I am always playing tag between one of these four doctors trying to figure out</i></p> <p>Medication interactions were also a common problem for many patients.</p>
CO32 Greenhalgh, Trisha et al. - 2010	<p>Low uptake of HealthSpace seemed to be partly because of patients' limited interest²⁴ and partly because the registration process was cumbersome and bureaucratic</p> <p>They need to come in to, like the front office, because we check all their identification documents that they need. I have to sign to say that I've seen the three proofs of ID.</p> <p>In this context, HealthSpace with its complex registration procedure, password controlled access, and self completion data fields was described as "faffy" or (more commonly) not considered at all</p>
CO36 Wilkinson, Emma et al. - 2014	<p>the DESMOND sessions suggested that the amount and timing of information was problematic for people recently diagnosed with diabetes</p> <p>they might have found it more useful for education to be delivered in a more staggered way</p> <p><i>It was an awful lot of information to take in</i></p> <p><i>the older you get the less you retain anyway. Well, I do.</i></p> <p><i>information is a good thing but sometimes it can be a bad thing in the sense it causes more anxiety</i></p>
EN15 Maten-Speksnijder, Ada J. et al. - 2016	<p>NP tells them that the blood results are not good and the young woman says, 'just as I expected, I am so tired'. The NP says that she regrets that the serumcreatinine level has risen. Then, events rapidly accelerate. The NP calls the physician in for a consultation, and he tells the patient a percutaneous nephrostomy is needed to save the kidney transplant. The husband remains silent; his wife asks for some explanations. After the physician has left the room, the NP informs the patient how she can manage the catheter at home. The NP has to arrange the hospital admission, and she asks the couple to wait in the full waiting room. The NP works quickly because she is already running 20 minutes late. Eventually she informs the couple in the waiting room where they are expected to go</p> <p>The NPs expected patients to put the disease at the forefront of their lives</p>
EN24 Powell, Rhea E. et al. - 2016	<p>patients being provided with insufficient information or with too much information without proper explanation. "<i>Because when you're being discharged from the hospital, it's a blur of you talk to 10 different people about 10 different things</i>"</p>
EN45 Young, C. et al. - 2016	<p>statistical data were not desired</p>
EM11 Nota, Ingrid et al. - 2016	<p><i>When I was younger they gave me medication and occasionally I heard what it was, but I don't think they properly explained what the side effects were or could be. Now they do, but now it is tough, because I sometimes get medication which makes me think: do I dare to start using this?</i></p>

ANNEX 2: Health literacy - Quotations and sources

Table 10 - Health literacy and self-directed learning

CO01 Sacks, A. Abt et al. - 2016	<p>when I see a word I don't understand, first thing I do first is look on the Internet</p> <p>I also ask her when I find out about another possible solution</p> <p>hear from a friend who is receiving a different treatment.</p> <p>I also like to have a lot of information</p> <p>This is reason why I am in the association</p> <p>if I got the information beforehand, let's say, a week before the next appointment, I think over and over again whatever little I know, talk about it, look it up, search it on the Internet to see the pros and cons</p>
CO04 Delea, Sarah et al. - 2015	<p>But if you're given diet charts and you're told all about it and what to have and what not to have</p>
CO06 Graves, K. et al. - 2011	<p>access to knowledgeable genetics specialists</p> <p>African American women have figured out that the sisterhood thing really works</p>
CO08 Dowling, Joni E. - 2010	<p>relied on the Internet as their primary resource when seeking information to assist them in making decisions about their care) sought a second opinion</p> <p>changed physicians when they were dissatisfied</p> <p>used the Internet to assist her decision making. In her research, she found a test called CYP2D6, Cancer Society (www.cancer.org), Breast Cancer.org (breastcancer.org), Susan G. Komen (www.komen.org), and Young Survival Coalition (youngsurvival.org), to get information to assist them in making decisions. Y</p> <p>She also relied on a wellness community in her area where she went for advice about local doctor helpful for her to hear from other women</p> <p>did her own research</p> <p>getting second opinions</p> <p>The first thing I did was cruise the Internet</p> <p>It was a great help. I knew what my options were from researching it on the Internet.</p> <p>I did my research on the clinical trials that he was suggestin</p> <p>. I talked with lots of other women</p> <p>met a woman through a support group</p> <p>support group for young women w</p> <p>support group</p> <p>active member of a BreastCancer.org blog where women talked about their treatment, which helped her he heard this happens after chemotherapy and radiation</p> <p>provide more information on topics such as preventing side effects of treatment, to offer research findings on effects of cancer drugs and fertility</p> <p>to distribute a recommended list of Internet Web sites.</p> <p>wished for a list of recommended Web sites to assist women in the decision- making process</p>

	I read the Internet and asked peers, then wrote down questions for the next time I saw the oncologist. purchasing books on breast cancer, libraries
CO12 Rubio-Rico, Lourdes et al. - 2014	instead through his friend, he has come to ask
CO13 Venetis, Maria K. et al. - 2018	The use of because clauses is associated with arguments/reasoning by the provider for a particular course of action rather than for simply providing information for the patient. , the provider is specific and targeted in the information provision, uses a higher frequency of concrete and group nouns, uses nouns that mark the information exchange as impersonal, and does not include causative clauses patients would anticipate high degrees of informational speech from their provider, particularly as this visit is often the first that follows the diagnosis. Research has documented that breast cancer patients have high informational needs
CO14 Hersch, Jolyn et al. - 2013	stimulating a search for other screening modalities knowledge might also give such women more of a sense of control Others felt that it was good to know about overdiagnosis in order to be able to make informed decision I really think it's good to know the downside of overdetection. ... That information [is] not discouraging me to ... screen, but it just made me feel I have knowledge , balanced information as the most ethical approach to communicating about screening people should be made aware that the information is there if they would like it ... this might help you make a decision
CO15 Hart, Ruth I. et al. - 2017 I. et al. - 2017	t the booklet had upon them, interviewees typically reported that it had made a difference to how they thought about fatigue, and that this was of real value Understanding fatigue helped to allay fears that fatigue was a sign of another, undiagnosed health problem or an inevitable age-related decline: gave interviewees access to new ways of defining and describing their experience enabling and encouraging the discussion incorporate into your life to make you feel better powerful motivator for change useful think about it and maybe analyse it, analyse what you're doing their approach to managing fatigue, and reported making, or planning to make, small but potentially significant adjustments to their behaviour participant information documents explicitly linking fatigue and arthritis, and recruitment conversations reinforcing this)
CO19 Brez, Sharon et al. - 2009	need for updated information and experience
CO20 MacDonald, Kath et al. - 2015	Just grew up considering the implications of investigations.
CO21 Berry, Judith A. - 2009	NP gives information, gives opinion asks for information history with open-ended and closed-ended questions, or seeks patient ideas
CO22 Smith, Sian K. et al. - 2008	friendly, easy to read, clear and not too intricate presenting health information in a direct, short and sharp way to increase retention and motivate the reader to use the material. The less you have to read the better Condensing the amount of text the value of tailoring information to suit readers with different literacy demands translation of medical terms using a simple glossary

	<p>Attitudes towards the illustrations varied. Lower literacy participants were generally positive about their use, and perceived the visuals to grab the readers attention and enhance text comprehension</p> <p>I thought they were quite good. So, even if youve missed out a bit of the information, the picture helps a little bit</p> <p>use of medical diagrams (images of the colon) were universally well received</p> <p>evaluate outcomes in the context of their own values and preferences</p> <p>different patient story examples.</p> <p>Higher literacy participants thought the patient stories were useful for someone with no prior knowledge. It returns us to a real life situation of someone elses predicament and forces you to make an assessment of your situatio</p> <p>concise, simple and direct</p> <p>scientific references as extra information was generally welcomed by those with higher literacy</p> <p>reassured them that the factual content had been rigorously researched</p> <p>t comes back to knowing where to go to get relevant or informed information from a reliable source.</p> <p>provision of additional sources of information</p> <p>telephone helplines</p>
CO23 Davies, Jane et al. - 2014	<p>previous education programmes</p> <p>d research projects carried out in the community</p> <p>increased understanding of biomedical concepts around infectious diseases</p> <p>; to ensure the individual translating has adequate understand- ing</p> <p>to allow/enable contextual translation,</p> <p>to communicate the message via the interpreter in the appropriate language</p> <p>to check understanding in language</p> <p>to ask the interpreter to back translate the participant's understanding and to clarify any miscommunication</p> <p>not to simplify the message too much such that the detail was lost.</p> <p>accurate but "culturally safe" concepts</p> <p>preference for visual aids</p> <p>passionately voiced a desire to understand</p> <p>she wants to learn more</p> <p>she can pass the story to her peopl</p> <p>to encourage them to come to the clinic and have a check-up</p> <p>strong desire to understand the detail</p> <p>preference for an electronic format</p> <p>interactive pictures and less text.</p> <p>it must be in Yolŋu matha and spoken as well as written</p>
CO26 Wray, Ricardo J. et al. - 2009	<p>Mass media were highlighted as important potential channels of information about prostate cancer and screening</p> <p>Local organizations</p> <p>local businesses (pubs and barbershops), health care institutions, insurance providers, churches, community groups, and fraternal organizations.</p> <p>Social and interpersonal channe</p> <p>family and friends</p> <p>prostate cancer survivors, especially, were perceived as credible and compelling sources of information</p> <p>Survivor discussions got the full attention of participants,</p>
CO27 Dolce, Maria C. - 2011	<p>Cancer survivors and caregivers learned about the latest cancer treatments and were able to access the best available research</p> <p>online support group</p> <p>e-mail contact with persons who answered my questions, helped reduce my fear, and helped me come to terms with my diagnosis</p>

	<p>I learned via their feedback that I had been misdiagnosed and that my doctor really didn't have enough experience to manage my case</p> <p>the Internet to diagnose themselves</p> <p>I do like reading about what is out there and wish doctors kept up with it, too. Totally disenchanted with my doc, as you can tell.</p> <p>As time went on, I realized I wasn't getting the correct information from my oncologist, so I decided to browse the Internet for myself.</p> <p>I diagnosed myself using online resources</p> <p>a lack of informational support related to procedures and were better prepared after seeking information on the Internet</p> <p>[I] faced surgeries with a very good idea of what was to happen, sure did not know this prior to first surgery</p> <p>Another survivor found reading blogs written by other patients who had experienced a procedure to be helpful and wrote, "I could better relate to their experience and it helped to know what to expect from a physical and emotional perspective."</p> <p>required practical information to help them manage their illness at home</p> <p>found help from their online communities</p> <p>Stories were shared about needing "emotional support" and turning to online communities.</p> <p>grateful for the Internet</p> <p>the ability of patients to connect with one another and become empowered and teach their doctors to allow them to be members of the team</p> <p>The Internet allowed me to track down a couple of journal articles relating to this [off-label] use, which helped persuade my doctor</p> <p>Thanks to the Internet, I pushed for what my daughter needed</p> <p>Cancer information verified through online resources influenced survivors' choices and care decisions.</p> <p>I was able to get information about treatment of carcinoid that conflicted with what my oncologist said— so I sought several specialists' opinions and they all agreed, but conflicted with the oncologist</p> <p>I did my own research online and then consulted with the members of my list.</p>
CO29 Reimann, Swantje et al. - 2010	<p>make referrals/ quality of referrals</p> <p>Education about illness and treatment</p> <p>(were the explanations understandable to you?)</p> <p>comprehensibility</p> <p>All of my questions were answered</p> <p>information on self-help groups or nutritional advice</p> <p>written information</p>
CO31 Zulman, Donna M. et al. - 2015	<p>tools that could provide information about their multiple conditions, such as websites</p> <p>Online resources that consolidate information about MCCs</p> <p>Bundled apps for MCCs</p> <p>Online support groups</p> <p>Now I research the medications before I take them together.^</p> <p>Many patients had experience using technology to detect potential medication interactions</p> <p>research everything you can</p> <p>this research was something done independently of interacting with medical professionals</p> <p>...tried to arm myself with enough information with the technology, with the right care providers so that I control the disease; the disease doesn't control me</p> <p>patients desired resources that consolidate and synthesize information about MCCs, such as applications that help identify potential medication-medication or condition-medication interactions.</p>

CO32 Greenhalgh, Trisha et al. - 2010	<p>One participant who had tried HealthSpace, later became interested in downloads for a digital personal organiser (iPhone apps) and found these more fit for purpose than HealthSpace.</p> <p>They tended to get this from other people, such as relatives, local diabetes support group, Face- book, and a nurse led telephone helplin</p> <p>online self help group hosted by a charity for patients</p>
CO33 Vilhauer, Ruvanee P. - 2014	<p>it was great having a support network, you know, in my computer room</p> <p>When I wanted to interact with people and when I didn't, it was totally under my control.</p> <p>information is still there</p> <p>t it's a treasure trove</p> <p>networking with other women with the disease that most of this information is acquired</p>
CO35 Goddu, Anna P. et al. - 2015	<p>In sharing stories, practical knowledge was transferred, and common issues were worked through collectively</p> <p>ole-play enabled group learning and discussion, helping to transfer knowledge and aiding in retention of information</p> <p>They also perceived that social proliferation increased their relevant knowledge and taught them skills to undertake behavior change.</p> <p>discussing these stories in a social setting generated teachable moments, which made the material more relevant and memorable for participants, facilitating knowledge acquisition and retention, and changing attitudes/beliefs about the stories' messages.</p> <p>You learn more with a group than you do just being on a one-on-one basis because in a group everybody experiences something different or simil</p> <p>family members were a good source of information</p>
CO36 Wilkinson, Emma et al. - 2014	<p>DESMONDb programme or a shorter locally developed alternative for non-English speakers</p>
ED5 Albarran, Cynthia R. et al. - 2014	<p>informational brochures</p>
ED6 Burda, Marika H. F. et al. - 2012	<p>professionals in the field of diabetes;</p> <p>) information booklets on diabetes and hypoglycemia</p> <p>websites about diabete</p> <p>diabetes education courses teaching knowledge and skills to recognize and manage hypoglycemia and prevent</p> <p>(d) DIs as experiential experts and the telephone helpline of the DVN.</p>
ED8 Sekse, Ragnhild Johanne Tveit et al. - 2014	<p>By gaining more knowledge about their own situation, such as the possible bodily changes and impacts on everyday life, the women understood themselves and their bodily changes better.</p> <p>knowledge was redemption,</p>
ED9 Santos- Livengood, Christie A. - 2015	<p>receiving their sexual health knowledge from the Internet, friends and health care providers, and trust their doctors above other sources</p> <p>"As I said, I get all of my sexual health information from my doctors. That's the only person I'm gonna trust with that kind of information."</p>
EM06 Phillips, Janice et al. - 2011	<p>I would like to get information specific to the younger age bracket, like the age bracket of people that aren't eligible for mammograms and like, I don't know if this is an option, but lifestyle adjustments or things that could be done to help reduce the risk of getting cancer</p> <p>I think more women—definitely younger, black women—need to pay attention to their bodies. They need to know their bodies; know what's changing and not be afraid to say, 'hey, something doesn't feel right.'</p>
EM08 NANTON, V. et al. - 2011	<p>information was important (if you get the information it helps you to cope) only the three youngest had actively questioned their doctors, though several had sought information from books and the media.</p>
EM10 Peterson, Jennifer L. et al. - 2012	<p>Peer Support</p> <p>peers are the only people who can share information about treatment experiences, this is an important function of peer support.</p>

<p>EM12 Wiljer, David et al. - 2013 EM12 Wiljer, David et al. - 2013</p>	<p>Participants believed the SC provided abundant and useful information resources available to support their health condition and treatment options and reported that it enhanced their understanding and awareness about their diagnosis and treatment option</p> <hr/> <p>Interest in seeking out additional information regarding the support services available for their emotional and social support was expressed.</p> <hr/> <p>Participants reported the SC helped them become more in charge of managing their own care by providing them with the resources, information and the organizational skills that they thought necessary to help them through their cancer journey. Participants reported feeling more empowered and hopeful.</p>
<p>EM13 Kowitz, Sarah D. et al. - 2015</p>	<p>PSS were more likely to report providing information for diabetes self-management</p> <hr/> <p>Providing information was also a way of reinforcing peer empowerment; gaining trust to establish relationships with peers, particularly in the beginning of peer contact; and alleviating people's anxieties, fears, and stressors</p>
<p>EM15 Taylor, Francesca et al. - 2016</p>	<p>peer support</p> <hr/> <p>To learn, share experiences, you know, get an idea of what's coming up next. What should I expect, you know, if I encounter a problem?</p>
<p>EM16 Vries, D. H. de et al. - 2016</p>	<p>By disclosing, the participants feel that they can educate people about HIV themselves. A Dutch campaign called "HIV uit de kast" (HIV coming out) is an example of PLWHA educating other PLWHA about disclosure to fight stigma.</p> <hr/> <p>people will see what a person with HIV really looks like. One participant illustrated this point by saying "[I disclose] for educational motives . . . to show people we are not sick, we are not dying, and we are not contagious" (R 100). One participant, for instance, said that disclosing is the only way to "break the silence of HIV" (R 267). Another participant said that disclosure is a way to "fight prejudices" (R 335)</p>
<p>EM17 DiGiacomo, M. et al. - 2015</p>	<p>One participant spoke of a female specialist who always books an interpreter for patients from non-English speaking backgrounds, regardless of accompaniment of a family member</p> <hr/> <p>There wasn't always enough [interpreters]. Um, it depends on the language, too; some are hard to get. Maybe Turkish or something like that might be hard to get. But we had their [phone] numbers and we certainly used to ask if they wanted an interpreter, because we didn't like their family accompanying them in to the doctor, because a lot of those women wouldn't want to say various things in front of their children, for example,</p>
<p>EN01 Ekundayo, Olugbemiga T. et al. - 2012</p>	<p>Prostate support groups.</p> <hr/> <p>Dr. Frazier, Dr. Ron Davies, Dr. Ross, Dr. Morrison, are some of the health care providers in the community.</p> <ul style="list-style-type: none"> • Most of the hospitals have urologists. • Family medicine physicians like Dr. Robert Smith may refer to urologist <hr/> <p>Information like DVD's,</p> <ul style="list-style-type: none"> • Might implement with education, • Bringing pressure to implement the policies <hr/> <p>Education means not just books, but spreading information through prostate cancer survivors and sufferers in form of personal testimonials.</p>
<p>EN03 Locock, Louise et al. - 2011</p>	<p>Access to better information or help with decision-making</p> <hr/> <p>enriching personal life, e.g., learning new things, meeting new people, social interaction</p> <hr/> <p>participating in a trial as a means of gaining information and reassurance about health-related issues important to them</p> <hr/> <p>intellectual curiosity about their condition, understanding how trials are run or finding out about the latest treatments.</p>
<p>EN04 Cook, Catherine - 2012</p>	<p>I think online talking is very good as you can speak to people in the same situation who are having the same problem</p> <hr/> <p>The internet has been my most used resource about HSV. It's available 24 hours a day to answer any questions I have. It</p> <hr/> <p>I found the herpes website to be most informative as the doctor is too expensive just to go to for a chat</p>
<p>EMOTIONAL FEELING DIMENSION</p>	

EN05 Graffigna, Guendalina et al. - 2014	<p>Psychological support for elaborating and accepting the diagnosis Elaboration of a better self-image (from "diabetic" to "person") [...] Good doctor-patient relationship for feeling understood and holdto feel "guided" COGNITIVE THINKING DIMENSION Deep information on the disease characteristic, life expectation, rational of therapy and lifestyle change Deep information on therapies function, value and rational [...] Support for translating abstract medical recipes into practical conducts I think I need to understand better why I need to take this therapy and for how long I search the Internet in order get answers."</p>
EN08 Carlisle, Karen et al. - 2017	<p>Community groups played an important role in sharing information to their existing networks</p>
EN15 Maten-Speksnijder, Ada J. et al. - 2016	<p>The NP's explanation of the origin of the symptoms transformed Ann's dismissive attitude into openness. NPs used brochures and websites from patient organisations, or referred patients to trained nurse counsellors</p>
EN24 Powell, Rhea E. et al. - 2016	<p>navigate a complex and fractured health system. I think the systems are completely broken and completely just un-navigatable... I have a Master's degree, and I have trouble talking to the County Assistance Office. T</p>
EN25 Robinson, Nicola et al. - 2015	<p>Using public awareness/education campaigns to engage patients, and tying in advocacy with PPE</p>
EN32 Hogden, Anne et al. - 2012	<p>The sources of information patients accessed were considered to influence participation in decision-making. "I think if we had more evidence for everything we do it would make life much easier</p>
EN34 Natale, Anthony P. - 2009	<p>desire for ongoing community updates on HIV/STI and other men's health trends was expressed MSM suggested that education efforts highlight physical, psychological, economic, social, and sexual effects of living with HIV disease. One suggestion involves creating a method, perhaps for the Internet, for MSM to assess how HIV impacts the lifespan, Textual representations such as pamphlets are limited in conveying the negative effects of living with HIV unless accompanied by frank and often graphic image When I think about some of the things that affect me visually, those things are hard to see, and are the ones that stay with you for a long time. Especially since there are so many competing things trying to get your attention. So you have to use many ways of getting the message out, but for sure it has to be visual. appealing to physical vanity among MSM I think that you need to use scare techniques; before and after pictures. raising awareness to the difficulties of HIV treatments on the human body a reorganization of STI informatio Participants voiced a preference for STD risk information by sexual behavior rather than by disease. identifying specific risks for infection by behavior I would like to see STD information grouped by oral, anal, kissing . Develop groups and workshops. Safe sex workshops are what I am looking for, for my partner and I. We want to learn more information about safe sex and we can't get it. I am not sure how you would do this, but education on the Internet would help. Not questions that people can read and sift through the information. I think that it needs to be more specific. Like what are the risks for oral sex, and what are the risks for anal sex.</p>
EN35 Gien, Lan et al. - 2017	<p>With limited access to information, rural residents often relied on informal supports such as family, neighbours, peers or church groups Obtaining information (%) Books/newspapers/magazines (21%); Internet (12.5%); Digital Recordings (6%); health professionals (69%); alternative sources (25%)</p>

EN37 McCabe, Catherine et al. - 2014	Another thing about people on the internet you know at least if you look up what other people are going through you think oh I'm not that bad or you know it can make life a bit more bearable because during winter months I'm more or less indoors."
EN40 Rise, Marit By et al. - 2013	The dialogue and exchange of knowledge included information about management of the health service on the system level, i.e. economic and operational aspects, information about diagnosis, treatment options and patients wishes and needs on the individual level

Table 11 - Needed information; Diagnosing

CO01 Sacks, A. Abt et al. - 2016	In my experience, when they performed a mastectomy on me, a lot of information was held back. I believe that us patients are perfectly able to make decisions for ourselves and that we need to do it
CO06 Graves, K. et al. - 2011	psychological effects of knowing one's genetic status, false reassurance, guilt and challenges with family communication about genetic risk. individuals who receive their test results are not able to "go back" after learning about genetic risk false reassurance in which they underestimate their personal and family members' breast cancer risk false interpretation of test results
CO08 Dowling, Joni E. - 2010	they advised me not to go on the Internet because of getting overwhelmed with information easy to get caught up in something that is completely unrelated to you. 7 needed more information about side effects beforehand wanted more research information specific to young women the lack of information to be frustrating because physicians asked patients to make massive decisions
CO12 Rubio-Rico, Lourdes et al. - 2014	a limited promotion of the service among professionals, this means that they are underused Very limited access to translation/mediation resources Translation/mediation services not proactively organized
CO13 Venetis, Maria K. et al. - 2018	increased question asking is associated with decreased patient outcomes, and namely reduced satisfaction
CO14 Hersch, Jolyn et al. - 2013	"How do we know that things are being overdetected? How do we know that there are some cancers that move more quickly or become more malignant than others? ... Overdiagnosis assumes that these women, who have been overdiagnosed, have a cancer that is not necessarily aggressive ... Who determines what's an aggressive and a non-aggressive cancer?" a few women reacted quite defensively to the concept of overdiagnosis or questioned why it mattered many women did not seem motivated to make a well informed and carefully considered decision about whether to have screening "I'll still go [for screening]. ... Surgery's okay too, but ... anything else being needed, any chemicalsto be put through my body ... then that's where I stop and think and look at the statistics."
CO15 Hart, Ruth I. et al. - 2017	communication with health professionals (in primary or specialist care) appeared limited; for some, the initial interview was the first time they had talked about fatigue general difficulties with regard to communication in medical consultations the data suggest a number of barriers specific to fatigue. These include: reliance on a colloquial vocabulary ("so tired", "exhausted", "knackered", "wiped out", "done in"); u What you're always looking for is something specifically about you... (And) it doesn't say ankylosing spondylitis anywhere on ther With any information-giving, it needs to be reviewed.
CO22 Smith, Sian K. et al. - 2008	You want the information to be accessible to everybody, but there is a risk of some people feeling like their intelligence is being insulted. But I actually think it is critically important that the information is available to everybody

	<p>images were often viewed by this group as patronising, childish, and meaningless, and there was a strong emphasis on the importance of creating illustrations closely related to the text.</p> <p>Irrelevant pictures dont really add very much to the text...I think that any illustrations for some- thing involving health should have a purpose behind them</p> <p>lower literacy participants seemed confused by the patient stories</p> <p>the choice to screen or not. This notion was apparently unfamiliar and confusing, and raised concerns that the exercises may set up a situation which encourages people not to screen.</p> <p>those with limited literacy gener- ally referred to them as meaningless, irrelevant, I dont think you need to know who did all the looking and searching for it and everything. It is not going to mean anything to you.</p> <p>perceived barriers to obtaining and understanding scientific information</p>
CO23 Davies, Jane et al. - 2014	<p>The biomedical or “balanda” (white person) version of hepatitis B was very much seen as an alternative explanation; new information that didn’t exist in previous generations.</p> <p>eally nice materials that have been developed educationally and flip books and things. In my experience they’re rarely used</p>
CO26 Wray, Ricardo J. et al. - 2009	<p>low levels of knowledge among most African American men about prostate cancer, risk factors, and screening and treatment options</p> <p>few programs and services in place to inform African American men about prostate cancer</p>
CO27 Dolce, Maria C. - 2011	<p>lack of clinical expertise in treating their disease and, consequently, turned to the Internet</p>
CO31 Zulman, Donna M. et al. - 2015	<p>patients with MCCs have to manage a high volume of personal health information</p> <p>this challenge as a multiplicative one, with the Bpaperwork^ increasing with each health care encounter: BYou are trying to manage your health and, believe me, every time you see the doctor and you’ve got different conditions the paperwork just starts mounting</p> <p>It is challenging for patients with MCCs to find peers with similar combinations of condition</p>
CO36 Wilkinson, Emma et al. - 2014	<p>only a very small number (n = 1 out of 28) had received structured patient education at two of the three sites</p>
ED9 Santos-Livengood, Christie A. - 2015	<p>the sexual health education they did receive was limited to safer sex in the context of heterosexual behaviors. P</p>
EM03 Goldenberg, Shira M. et al. - 2016	<p>HIV/STI testing and counseling was noted as particularly needed for recent arrivals from other countries and rural communities, who often had limited (if any) previous exposure to HIV/STI prevention or testing, as most had not engaged in sex work prior to their arrival and came from more conserva-tive communities where access was constrained</p>
EM04 Boise, Linda et al. - 2013	<p>he little information we get is simply by talking to friends who have been here before us.*</p> <p>Well, I just don’t know much about the health care system here.*</p> <p>Information is often available but not in the right language though—that is important too</p> <p>Many refugees feel isolated and lack the necessary navigational skills to access the care they need</p>
EM08 NANTON, V. et al. - 2011	<p>their knowledge had been vague.</p> <p>Most of us didn’t get information before you got prostate. Most of us didn’t know about prostate, what it’s for you know</p>
EM12 Wiljer, David et al. - 2013	<p>Nutrition was identified as an area not ade- quately covered by the consult.</p>
EM17 DiGiacomo, M. et al. - 2015	<p>“...older women treat doctors like little gods up to a point</p>
EM17 DiGiacomo, M. et al. - 2015	<p>“Women used to come in and tell us things, a lot of things, you know, about their local doctors and how they didn’t listen to them, that’s a major one. And how they just pushed them off as long as they got them out of the place in five minutes...they would write a script,</p>

<p>EM17 DiGiacomo, M. et al. - 2015</p>	<p>especially with women with menopause, they were the main complainants...male doctors didn't want to know about it, basically</p>
<p>EM17 DiGiacomo, M. et al. - 2015</p>	<p>Health professionals may erroneously assume chronic disease sufferers or their caregivers, including those who may be health professionals, have acquired expertise and capacity for self-management throughout the duration of illnesses.</p> <p>The more chronic the disease, the less...interaction they get</p> <p>most informational resources are in English which makes it very hard for carers from CALD backgrounds to navigate the health system without support.</p> <p>The refugee health program linked women to a general practitioner, English classes, opportunities to increase health literacy, and information on reproductive health which was important to these women. Unfortunately, not all resources were in their language.</p> <p>For older women, in particular, who often have multiple chronic conditions, but whom are impacted by social, cultural, sometimes linguistic, and economic contexts that impede care, the silo-structure is a major obstacle. It was noted that although policy reflects the ideal of holistic care, it was expressed that workforce time constraints and structural inconsistencies mean holistic care remains an aberration.</p>
<p>EN01 Ekundayo, Olugbemiga T. et al. - 2012</p>	<p>disparity in health information access for African Americans.</p>
<p>EN04 Cook, Catherine - 2012</p>	<p>to decipher the research that is out there and filter out the propaganda and fear-based support groups (V</p>
<p>EN05 Graffigna, Guendalina et al. - 2014</p>	<p>the rationale behind medical requirements. "I try to be compliant with all my doctor said, but I confess that I didn't really understand the sense</p>
<p>EN15 Maten-Speksnijder, Ada J. et al. - 2016</p>	<p>mother says: 'I don't believe Femke really understands what is going on with her and the disease'. Femke reacts: 'I do understand, but I don't believe the half of it.' The NP shows Femke where she can find a lot of information about the disease on the Internet. She explains: 'this could be helpful to explain to others what it means to have rheumatoid arthritis.</p>
<p>EN18 Mitchell-Brown, Fay et al. - 2017</p>	<p>Yes, if they wanted us to get better, then maybe they would have provided us some education about diabetes. Because they don't, we always go in for visits to get medications</p> <p>, my doctor has given me a pamphlet in English about diabetes. But I cannot read it, I</p>
<p>EN24 Powell, Rhea E. et al. - 2016</p>	<p>to navigate the complex processes required to apply for and maintain insurance.</p> <p>A fear that I have is that some people didn't do it [enroll in ObamaCare], didn't understand it, or even if they understood it didn't do it the right way or what have you.</p>
<p>EN25 Robinson, Nicola et al. - 2015</p>	<p>cited needing practical information on 'best practice', to avoid 'rein-venting the wheel',</p>
<p>EN32 Hogden, Anne et al. - 2012</p>	<p>The Internet is so varied, that, we have patients regularly sending in information going, 'Oh, I've found this amazing machine that's going to solve all my problems'. And having to tell them, 'I realize you've found this and all the things sound really good, like online there's all these wonderful reviews about this system, but it doesn't work.'"</p> <p>noncredible sources lacked an evidence base, but were easily accessed via the Internet, such as websites selling herbal remedies</p> <p>concerned about the ability of the patient to discern between credible websites and those promoting false hopes of cures and treatments.</p> <p>Clinicians reported a sense of responsibility to monitor the quality of information accessed by patients, and to provide guidance on the range of evidence-based information available</p> <p>poor quality information compounded patients' difficulty accepting the inevitable nature of their condition</p> <p>to create unrealistic expectations of the services health professionals could offer,</p>

	Participants viewed the timing of information as dependent on the patient's readiness to hear
EN34 Natale, Anthony P. - 2009	The right messages haven't been found, because if there is an effective message, we wouldn't have all these problems.
EN39 Durme, Thérèse Van et al. - 2014	Patients lack accessibility to relevant information because (1) the legal framework organizing reimbursement systems and care delivery is too complex; (2) the role of patient organizations is too weak; and (3) information is not well-organized and is obsolete. As a result, patients (a) miss information and therefore lack access to tools to make informed choices
EN45 Young, C. et al. - 2016	clinical data were limited as they did not provide a holistic view of a person or their family's health.

Table 12 - Recruitment of participants for health promotion education

ED12 Caine, Vera et al. - 2016	<p>Support from the Canadian Association of Nurses in AIDS Care, Canadian AIDS Treatment Information Exchange, and ASOs was critical for recruitment of participants and in sustaining participant commitment. The tremendous support of the local ASO staff,</p> <p>One thing I should also add that's really been beneficial is I feel that I've made a connection to [local ASO]. I don't know how or why, but it wasn't established before, so that's a really good piece that's enhanced my role, b just having the physical space here has been a really good thing.</p> <p>We found that community size played a role in the ability of interested nurses to join the study. At rural sites, manager support was particularly high:</p> <p>Nurses at some urban sites had nonsupportive managers when they asked if they could join the study. O</p> <p>Other structural challenges for nurses to participate were related to the flexibility of their positions and their workloads</p> <p>We also found that mentees from larger urban centers had much more difficulty negotiating meeting times and had the least flexibility in arranging their schedules.</p> <p>, we all say we're busy, and I think if you believe in something strongly, yes, you can find time, but we've faced cuts to our staffing. (Urban mentee)</p>
ED16 Wright, Nicola - 2013	<p>None of the participants were referred onto self-management courses by their General Practitioners</p> <p>All your support should stem from your GP, they should be able to direct people to what's out there</p> <p>think there should be one big network like a tree with projects branching off it</p>
ED4 Blixen, Carol et al. - 2015	<p>Barriers to attendance were minimized with free car parking passes or bus vouchers for those who took public transportation</p> <p>Taking public transportation often involved long traveling times, but the vouchers proved an incentive</p>
ED7 Hurt, Tera R. et al. - 2015	<p>attract men to the program, it would seem to be best to emphasize a "desire to live longer and achieve a better quality of life" and "enhancing one's quality of life for themselves and their families."</p> <p>It must be stated that "preventative care is an investment in your health" a "You have to have a wow factor, like it will add 10 years to your life!"</p> <p>the program must be offered at a convenient time</p> <p>The program should be offered either for free or at a low cost.</p> <p>men reflected on their motivation for attending the focus group and the fact that being paid for this participation in part inclined them to attend.</p> <p>program format should facilitate fellowship and cultivate a sense of "brotherhood"</p> <p>"Men are likely to be more proactive if they have other men challenging them and holding them accountable."</p> <p>Men advocated for the program facilitators to be either Black women or men, but preferably men</p>

	<p>"It's very important that the facilitator be Black because of our lifestyles." T</p> <p>"The 20 to 30 age range is a bad range. They're [Black men] still trying to find themselves. Oftentimes they're working jobs with no benefits, including health insurance to cover doctor's visits.</p> <p>"You need to think outside of the b</p> <p>health clinic, church, grocery store, YMCA, or another community centre</p>
EM05 Oliffe, John L. et al. - 2008	<p>Group 6 had a 10-point charter that listed the group's aims and perhaps best represented the shared philosophy of PCSGs. Points 1 through 8 described how the group helped individuals. For example, the first aim was "to provide an opportunity to meet with other prostate cancer patients/survivors and their supporters." Points 7, 8, and 9 addressed broader issues including a commitment to prostate cancer advocacy, research, and raising public awareness</p>
EM10 Peterson, Jennifer L. et al. - 2012	<p>AIDS service organizations—Participants described involvement in ASOs, which brought them into contact with other PLWH. Based on the interview data, of the 43 (56%) who participated in ASOs, 12 (15%) said they both volunteered and received services, 9 (11%) volunteered, and 22 (27%) received services. Although participation in these organizations may not have been intended to provide peer support, it opened opportunities for interaction between PLW</p>
EM10 Peterson, Jennifer L. et al. - 2012	<p>A lot of times, like when we are waiting for our counselor or whatever, a lot of us will start talking about things. Also, they do social activities, like we went to the IMAX Theater. And they started a new group where they try to do social things off the property, like have a party at a bar or have a picnic, or things like this where we can even bring our friends and family and interact. It's very supportive, because you get to know different people, compare stories, and just be able to check up on one another.</p>
EM15 Taylor, Francesca et al. - 2016	<p>informal peer support</p> <p>incidental encounters at Renal Units.</p> <p>Respondents explained how their emotional 'mood' or 'frame of mind' at particular points might inhibit or motivate response to a desire to talk with another patient or carer.</p> <p>I think the nurses would be a great help because they obviously know what sort of people the patients are and they can perhaps encourage them. (Patient 14)</p>
EM17 DiGiacomo, M. et al. - 2015	<p>"I mean, those opportunistic outreach opportunity - like the shopping centres, community events or just community thoroughfares, those places where women frequent, I think having a presence, an appropriate presence by the health service...There's some work around mobile services in disadvantaged communities, which have been successful for women." (PS)</p> <p>neighbours and friend</p> <p>women use the verbal</p> <p>they want word of mouth, they have trust amongst their informal network</p>
EN01 Ekundayo, Olugbemiga T. et al. - 2012	<p>community spokesperson</p> <p>working through community identified centers of influence (clergy, etc),</p> <p>centers of living and social activities (barber shops, salons, churches, work places)</p> <p>transit (billboards, etc) w</p> <p>health professionals should be involved in health fairs</p> <p>Center of influences like church, pastor,</p> <p>Announcements through the mass media</p> <p>Work places</p> <p>Bulletin boards</p> <p>Commercials</p> <p>churches, raternities, sororities, barbers shop.</p> <ul style="list-style-type: none"> • Insurance, • Free screening <p>Reaching community</p>
EN07 Hout, Marie Claire Van et al. - 2012	<p>Several service providers reported a lack of potential client interest in the SUST due to its city location</p> <p>Like there's no drop-in ... do they expect clients to travel?</p> <p>as soon as you say XXXX [city], they say no way, forget i</p> <p>It needs advertising. You need to set up meetings,</p> <p>You need to set up a meeting. People are dubious about what they are getting into. (</p>

	<p>limited time</p> <p>transport</p> <p>Rural</p> <p>Internet is the only way. It needs greater cyber visibility, e</p> <p>Use online forums, however this can be problematic for middle- aged [individuals] who can't use computers,</p>
<p>EN08 Carlisle, Karen et al. - 2017</p>	<p>sought active involvement from a community of place (including citizens, health professionals, service agency, and local government staff)</p> <p>Needs assessment was conducted through discussion at planning workshops, meetings with other community groups, and participation in community events.</p> <p>Engaging Communities in Oral Health facilitators identified the key community groups, made contact via telephone/email, and then visited the key people</p> <p>it was essential that the After-Hours facilitators identified and worked with stakeholders in the catchment area.</p> <p>I knew the key players and networks I could tap in to and more importantly they knew me</p> <p>Easy-to-read flyers w</p> <p>Other activities included attending community events, visiting GPs and other local organizations, and meeting with community support groups, all to increase community awareness of the range of available</p> <p>After-Hours primary health-care options and assist appropriate service choices.</p> <p>[Medicare Local] distribute[d] promotional materials</p> <p>to general practices, Hospital Emergency Departments, primary schools, kindergartens, day care centres, tourism centres, holiday apartments, holiday accommodation, motels, hotels, pharmacies</p> <p>the community would prefer a familiar face.</p> <p>it keeps some consistency and you are a familiar face to people now</p> <p>"The group were satisfied that the implementation was tracking as expected. They queried the groups targeted (children) and suggested that some of the resources could be tailored for other groups</p>
<p>EN09 Flournoy, Minnjuan W. - 2011</p>	<p>word of mouth</p> <p>referrals</p> <p>The dissemination of information about the program via word of mouth occurred during the community-based support group meetings held by the case managers.</p> <p>The internal referrals to the dental services came from the primary care clinician and the case managers</p> <p>external referrals came from other community agencies and private practice</p> <p>support group meetings. Someone was there that had been and they had new dentures that looked real good. (</p>
<p>EN25 Robinson, Nicola et al. - 2015</p>	<p>me going into a barber shop and asking young African Caribbean men isn't going to be as effect as another African Caribbean young man going in ... there are issue of local community intelligence which we don't have (</p> <p>. varying communication methods, using innovative or mixed methods.</p> <p>Online methods, including Facebook, websites, virtual focus groups, and Google advertising</p> <p>I think you've got to have a range of different methods, because different things work with different people (P</p> <p>t's basically being aware of ways, how people like to communicate, and establishing effective communication</p> <p>We've tried to set up focus groups. Very, very difficult</p> <p>Using public awareness/education campaigns to engage patients, and tying in advocacy with PPE</p> <p>Working with voluntary sector organizations</p> <p>we can rely on the great British tradition of volunteerism, but usually that means, again, you're back into certain socioeconomic groups</p> <p>there is a big challenge in engaging potential service users...Why would you identify yourself as somebody who might want to use sexual health services in the future?</p>

	<p>in terms of people that we would particularly like to see more involved it's, sort of, communities who are more likely to be affected by poor sexual health and HIV, so, um, men who have sex with men; Black Africans; young people; people with HIV, um, so, you know, those are our sort of main target audience</p> <p>actively involve and oversample at risk groups,</p> <p>public events a</p> <p>advertising on TV and news- papers</p> <p>Snowballing (or 'viral' recruitment)</p> <p>Making it easy for patients, by providing expenses, payment, qualification, transport</p> <p>I'd be more encouraged to do something if you get your lollipop or something [incentive/payment] than if not.</p> <p>Make PPE activities fun, social, exciting or educationa</p> <p>Wanting to make a difference, give some- thing back, or a sense of community</p> <p>it is about, sort of, basically reaching out and listening and engaging in conversation</p> <p>Stigma made PPE recruitment difficult, especially for publically visible roles and group approaches, and limited 'real' involvement,</p> <p>confidentiality</p> <p>Stigma was dealt with through anonymous and confidential methods of PPE, education programs and using preformed group</p> <p>Collaboration with other organizations, especially VCOs, to access to 'hard to reach groups', it is just such a sensitive issue ...which is why we find it better to go into groups, you know, preformed groups</p> <p>churches/faith groups, youth clubs, football clubs, local councils, local media, colleges, universities and schools, LINKs, pharmacies, clinical units, charities, children's centres, and men's health groups.</p> <p>Ethnic-specific support groups were particularly common. [we] worked together with the BME forum, and they have sort of some history of consulting with their groups, taking guidance from them</p>
EN34 Natale, Anthony P. - 2009	<p>It's true that I think that the best way to reach Latino gay men is through language, if you do everything in English you are going to miss a lot of people</p> <p>They requested that HIV prevention programs be located within facilities that cater to their ethnic identities as opposed to their sexual behaviors</p> <p>I think that having a space is important for gay Latinos because they can come and take part in the community.</p> <p>A Latino place might also get these men to come in.</p> <p>involving Latino families</p> <p>BMSM identified religious institutions as unrealized partners in combating HIV transmission</p>

Table 13 - Facilitators of the health promotion implementation

CO08 Dowling, Joni E. - 2010	network of survivors near where they lived and worked. Y
CO26 Wray, Ricardo J. et al. - 2009	a multi-component effort must mobilize complementary media, institutional and interpersonal reinforcement in support of men
CO33 Vilhauer, Ruvanee P. - 2014	<p>Women who lived in rural areas with- out easy access to FTFGs</p> <p>It doesn't have to be locked into an hour on a Tuesday night.</p> <p>can take place on your own terms</p> <p>the level of support was greater in a CMSG than in a FTFG, because of the constant presence of fellow-members, archiving of support messages and/or the greater possibility of getting their concerns heard.</p> <p>In a CMSG, on the other hand, members can write as much as needed to convey their concerns</p> <p>found e-mail hampering be- cause of her high attention to detail.</p>
CO35 Goddu, Anna P. et al. - 2015	The experience of watching the film, of seeing stories played out, seemed important to making participants feel that these situations had "actually" happened. Most participants felt the film culturally resonated with them

<p>CO35 Goddu, Anna P. et al. - 2015</p>	<p>watching the film prompted emotions and reflections on their own experiences. discussion, rehearsal and social support.</p> <p>social support was generated among participants while sharing and rehearsing these narratives (in often lighthearted ways, e.g. pretending to be at a restaurant, with the teacher dressed as a chef). This social support reportedly changed participants' attitudes/beliefs, including their perceived social norms about health behaviors and patient/provider communication.</p> <p>'I can see myself</p> <p>I was a little shy but. . .I opened up more by listening to someone else telling their part</p> <p>You learn more with a group than you do just being on a one-on-one basis because in a group everybody experiences something different or simil</p> <p>It reminded me of my younger days</p> <p>I had been in that same position that the other people were</p> <p>kind of took heed of a lot of little things. . .and they kind of build me up</p>
<p>ED10 Costello, Joanne F. - 2013</p>	<p>a philosophy of shared authority and group ownership;</p> <p>One facilitator described her role in the group as changing from a traditional formal approach to one of informality with the group in charge</p> <p>One facilitator noted: I think my major goal is to not let them feel different. It's a balancing act. I want them to live normal</p> <p>[W]hat were really striking were the behavioral changes that were made. Not by what I as the expert said you need to do, but by peers saying, 'I've done this and this works.'</p>
<p>ED11 Dale, Jeremy et al. - 2008</p>	<p>professional, friendly and non-judgmental, and an opportunity to share information with 'fellow sufferers'</p> <p>felt more confident in managing their diabetes</p> <p>established a good rapport with their peer supporter and were able to share experiences and tips on how to manage their diabetes</p> <p>supportive comments and the positive feed-back, while acknowledging the limitations of peer support with regard to the provision of information</p>
<p>ED12 Caine, Vera et al. - 2016</p>	<p>"Like I felt that there was a big sign over me or something over my head that pointed me out and everybody was watching me now. I was very—I guess you'd say I got very self-conscious of myself" (Urban PLWH mentor).</p> <p>Mentors and mentees consistently shared that they had developed a strong, tight-knit group based on building collegial and trusting relationships</p> <p>they learned from each other over time regardless of whether they were in the role of mentor or mentee. A</p> <p>I think she [female PLWH] was instrumental. We learned so much from her ... we can read clinical guidelines all day long and learn from that, but it's that personal experience. And lots of times in clinical practice, we may have the odd client who is open and wanting to teach us, but that doesn't happen very often, so I think it was completely instrumental to have [PLWH mentor] there.</p> <p>(Rural nurse mentor)</p> <p>nurse mentor reflected that mentoring others gave her increased confidence in her own knowledge and that the group gave her the validation she needed</p> <p>Sometimes we don't really feel like we know very much, but then being in this role [nurse mentor] in the group has validated my knowledge and my experience, so I think that carries through when I go to work.</p>
<p>ED15 Goebbels, Adrienne F. G. et al. - 2012</p>	<p>he counselling encouraged them to change their lifestyle behaviours. T</p> <p>Well, I stopped smoking because of this [the counselling]. Well, I managed this and now it is also a matter of physical activity. It</p>

What were the most rewarding calls?

- People who were setting goals and implementing changes.
- 'I had [...] someone who kept saying that they would do some exercise and kept putting it off, then finally sort of admitted that they had been bluffing and they then started doing regular exercise.' (P52)
- 'I gave him the guidance to go and find out for himself more information about diabetes [...] He went to his practice nurse and he started getting regular educational sessions.' (D3)

- 'It was nice to know that there was somebody there that was going through the same things as I was'. (P3)

	<p>"I don't change my life because of it [the counselling]. Well, but it reminds you that you should watch out a little bit, that you have to live healthy."</p> <p>increased awareness of health risk</p> <p>"Well, I become more aware of it (. .) what I struggle with, every time. Because I want to change my lifestyle, but I don't manage to</p> <p>increased their motivation</p> <p>"When this moment of control is not there anymore, yes then it[motivation]is likely to abate. I really need a little bit of control</p> <p>helped respondents to set more concrete and realistic goals</p> <p>'feeling fresh and clean'</p> <p>overcoming addiction</p> <p>body satisfaction</p> <p>effort</p> <p>change in their body shape</p> <p>greater body satisfaction, which respondents described as finding themselves more attractive and being less ashamed</p> <p>to wear a smaller clothing size, which was associated with the possibility to find prettier clothes.</p> <p>learned that achievements, such as weightloss or increased endurance are a result of their own efforts to change behaviour.</p> <p>respondents who stopped smoking reported that they were happy to have overcome tobacco addiction</p> <p>individual participants also had spillover effects on the broader social and family environment</p>
ED16 Wright, Nicola - 2013	<p>backgrounds and levels of education</p> <p>companionship or social support they got from other attendees</p> <p>I got from it that I was valuable, I had never got this from my family, I was never valuable to my family.</p> <p>I got out of it most was helping other people, helping other people who hadn't had their illnesses as long as I had and were still coming to terms with it</p>
ED2 Barlow, J. H. et al. - 2009	<p>more information and support about coping with the psychological consequences of living with MI.</p> <p>reappraised their situation as being 'more manageable' and became re-engaged with life,</p> <p>A few participants felt that that had not 'improved or got worse in terms of MI-related problems' but nonetheless they felt 'a bit more positive.'</p> <p>'I think it brought me out of myself. It made me a lot happier in myself</p>
ED4 Blixen, Carol et al. - 2015	<p>comfort and cohesiveness among group members.</p> <p>But then after we all got together and we all started talking about our own issues, it was really quite open and I felt really comfortable."</p> <p>some of the things that they talk about that I had to learn about myself and to get with myself with that way of life when I found out about my diabetes and my serious mental illness. It was a wonderful experience and I enjoyed it and I would do it again."</p> <p>if we had questions about it we were encouraged to ask those questions, and also keep in mind that we were going to be answering those questions for someone else</p> <p>"I think what I've tried to do is try to expand, the manual can be a bit didactic and some patients aren't on the same learning levels as others. So on some occasions when I think it was appropriate, I'd bring in something from the outside to the TTIM class.</p> <p>"We always had materials handed out on part of the sections that we went over and that we were going to be working with for the following week so that we can study it and, you know, have some knowledge about it beforehand." Respondent 1</p>
ED5 Albarran, Cynthia R. et al. - 2014	<p>Among the helpful aspects of the programme were the tools that women found useful. These included a pedometer and the actual tangible feedback they received through a series of health assessments</p>

	<p>Promotoras taught the women how to use the pedometer and personified it by giving it a nickname that the women adopted: the 'panchita' (a nickname for the female name 'Francisca').</p> <p>family members encouraged them</p> <p>'confide in [promotoras] and talk about our problems, our worries,'</p> <p>they received valuable practical help</p> <p>The motivation gained from promotoras was crucial to the women because it increased their sense of self-worth.</p> <p>The emotional support the women received appeared to be an unintentional byproduct of the programme</p> <p>sharing in an open forum,</p> <p>sharing relationships and building trust among women</p> <p>Women perceived promotoras as direct links to medical professionals and expected them to be proactive</p> <p>Participants also valued promotoras who had experience in their role – they could tell who had prior experience and who was just learning for the first time.</p>
ED7 Hurt, Tera R. et al. - 2015	<p>give attention to the importance of masculine roles and how the recommendations could increasingly motivate men to meet their family obligations.</p>
ED8 Sekse, Ragnhild Johanne Tveit et al. - 2014	<p>feeling of togetherness with peers, who had been through gynaecological cancer</p> <p>It's the togetherness... we have been more or less in the same situation... Everyone knows what it means to have cancer... and talking about it in a safe place where it is okay not to be healthy, or to be healthy, but still carry that 'luggage.'</p> <p>strong feeling of community</p> <p>There's something about the sense of community that has become very strong... despite the fact that we don't know each other... but yes, there is something that ties us together.</p> <p>I've been through death many times... but I was relieved of these thoughts when I joined this group.</p> <p>'The fact that we have a common fate is important... That is why we can talk together'.</p> <p>telling their own stories and being understood</p> <p>has been good to take part in other people's experiences, to learn how others have handled it and to feel that I can contribute with my experiences.</p> <p>Listening to others sometimes led to increased understanding of one's own situation.</p> <p>Shared experiences provided a confirmation of normality</p> <p>To be in a setting where I'm normal... a place where nobody says 'you poor soul!'... A place where you can share the good and the bad...</p> <p>that others feel this way too and think the same thoughts, share the same thoughts I have had...</p> <p>Through education, guidance and the sharing of experiences, the women gained a clearer understanding of, and vocabulary for, bodily changes. This provided them with answers and insight.</p> <p>Within the safe boundaries of the community, the women exchanged experiences and expressed their own thoughts.</p> <p>I had no idea that I would learn so much. When I was asked to participate, I thought maybe we would be helping someone who came after us, not that we ourselves would receive help</p>
EM02 Miller, Robin Lin et al. - 2012	<p>For Mpowerment Detroit, the economic and educational challenges facing young men are of paramount concern, as is assisting young men to obtain the life skills that may be less readily available in a setting that is poorly resourced</p> <p>complete their resumes, preparing them for job interviews, teaching them how to tie a tie, and helping them to secure housing and food.</p> <p>metal door with a barred window that is covered so that no one may see into the space from the hallway.</p> <p>Mpowerment Detroit staff and members are convinced of the importance of making serious attempts to address HIV through rigorous forms of outreach, referrals to testing, and addressing the range of issues that may promote risk</p>

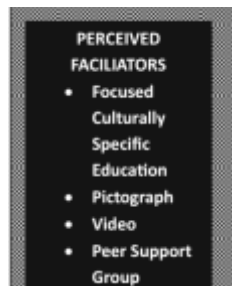
	<p>leadership</p> <p>cultivating brotherly relationships within the member community, leadership development, and facilitating members' success in the outside world</p>
EM05 Oliffe, John L. et al. - 2008	<p>cohesive, committee-based leadership that used a "divide and conquer" approach was most likely to result in effective and sustainable</p> <p>Many of the groups prided themselves on the way they functioned and recognized their contributions to local as well as global populations of prostate cancer survivors in many ways.</p> <p>Survivorship was a strongly represented idea</p> <p>the primary influence on the sustainability of PCSGs lay in the groups' commitment to and capacity for activism.</p>
EM06 Phillips, Janice et al. - 2011	<p>I wanted to do like a group with the women [in my family] so we could talk about our health history and talk about what we need to do</p>
EM08 NANTON, V. et al. - 2011	<p>if there is a problem they can come and ask me.</p> <p>You know I don't know everything but I've got through a lot since day one – six years now . . . people can just ask. (Mr P)</p>
EM09 Grande, Stuart W. et al. - 2013	<p>"keeping each other on their toes" and "challenging each other" to make better decision</p> <p>Participant 14 thought about his responsibility to other African American men, "this goes back to the teachings of Elijah Muhammad. If you see someone with a dirty glass offer them a clean one. And see which one they drink from. You did your part. That's it."</p>
EM10 Peterson, Jennifer L. et al. - 2012	<p>Of the 81 participants, 73 (91%) had friends or family members who also were infected with HIV, 45 (56%) received services or volunteered in an AIDS service organization (ASO), 24 (30%) attended a support group, and 10 (12%) participated in a one-on-one peer support or buddy program</p> <p>Right now I am currently in two [support groups], one is an HIV-positive group and the other we call an open discussion group. I've met and talked with a lot of people who are HIV positive. Basically, they are set up in a very informal atmosphere. We go around and check in and if anybody has anything important to talk about then they either take their time and talk about it then or we just do a quick check in and come back and let them discuss whatever is important to them at that time.</p> <p>Support groups that meet online are increasingly being used</p> <p>It's a bunch of nice people in there. Once in awhile we talk about the medication we're taking, who's been positive how long, how they have dealt with it, what has been the worst part, and just chat with other people. A lot of the people in there have actually been meeting each other. The only problem there is that it's located on the West Coast so that's kind of bad for us Midwest and East Coast people. They have organized cruises they take every year. I was considering maybe doing that just to mingle.</p> <p>a buddy system</p> <p>Typically one of the research nurses would call and let me know that a patient was coming in that was newly diagnosed and wanted to talk with someone. I would come here and spend an hour, even more talking with that person, more listening to them than talking. Listen to their fears and in many ways relive my own experience, which at times is kind of hard. Offering support to the person who was newly diagnosed by letting them know that all of the feelings that they were going through were completely understandable, were normal, were typical, and believe it or not they were going to pass and they would move on to other things. Basically I would like to think that I served as an example to folks who were newly diagnosed in terms of how one can live and manage the disease in a healthy way.</p> <p>Providing support to others has been shown to be therapeutic in other contexts (B being a "buddy" can lead to mutually supportive interactions. In the context of HIV, buddies assigned to provide those newly diagnosed with support have also been found to experience social acceptance as well as personal growth and empowerment</p>

	<p>s, peer support ranges across the various functions that Dennis (2003) described (i.e., informational, emotional, and appraisal). Additional forms of support that have been defined elsewhere were also present, including instrumental or tangible support, esteem support, and network support. Tangible support, or the provision of goods and services,</p> <p>Things I wish people would have did but, even washing dishes.</p> <p>Informational support</p> <p>we talk about different medications, about alternative therapies I've used and recommendations for treatments beyond my medications, more holistic types of things, acupuncture and other things.</p> <p>peers are the only people who can share information about treatment experiences, this is an important function of peer support.</p> <p>"Well, sometimes in a larger group, you're willing to do more. I'm willing to do more risk taking in some areas because these are not people that know me well, we've just come together for this reason."</p> <p>I've talked one-on-one and in a support group but I mean, in a support group you get a lot more feedback from other people "Oh well I've been through that" or "this is what I did" versus one-on-one the person says, well you know, either "I understand" or "I don't." So I think with the support group, there's a lot more feedback and a lot more people throwing stuff out there than just one other person's opinion - but both are valuable.</p> <p>a basis for meeting people who they might not have otherwise met</p> <p>It is kind of interesting - the group - there's a large variety of people that go there. We have one guy who actually works for the university here, and we have another guy that is married and is now going through this nasty divorce because he was HIV positive. Then we have a woman that comes to the group, and she was bringing this guy that she was dating that he found out that he was HIV positive just recently, but then he all of sudden stopped coming. And then we have another guy that is very financially wealthy to the point where he basically financially supports himself, o</p>
EM12 Wiljer, David et al. - 2013	<p>"...that encourages me quite a lot to seek out the program and find out more about it..."</p> <p>"...I had a better understanding about who I could turn to for what because it is a little confusing...you do end up having several different doctors, sev</p> <p>I learned about my cancer, about my stage, [the clinician] helped me understand that a little bit better.</p> <p>I wasn't sure whether that changed with the treatment and [the clinician] helped me understand..."</p> <p>"It verified some things...what to expect after some of the treatments, effects on my body, like the exhaustion. I was telling [the clinician] some of the things I was experiencing..."</p> <p>"...I already have a pretty good understanding of my diagnosis. I don't think [the clinician] could have really told me anything that I didn't already know."</p> <p>...fatigue is a huge issue so [the clinician] mentioned that...I was complaining that I was somewhat brain dead...[the clinician] mentioned...good recommendations..."</p> <p>"There's a lot of confusion about taking care of yourself and how best to do it... Nutrition I feel like is a big one that was not covered."</p> <p>"We talked about groups and clubs, always looking for speakers and that type of thing. I think [the clinician] had a clear understanding of where I was coming from at that point. [The clinician] really addressed that..."</p> <p>"...the opportunities in the community for helping different areas...really good to know that they're out there...I feel like it's important to know that they're there...a lot of patients do want to use those support systems."</p>
EM13 Kowitt, Sarah D. et al. - 2015	<p>PSs were more likely to report providing information for diabetes self-management</p> <p>"People weren't looking for emotional support. I think it just came into play. Sometimes people may not know exactly what they need but once they are a part of something, they get to see." Over time, PSs in all projects</p>

<p>EM13 Kowitt, Sarah D. et al. - 2015 EM13 Kowitt, Sarah D. et al. - 2015</p>	<p>reported coming to provide substantial emotional support after developing relationships with peers.</p> <p>ow they provided emotional support, they often mentioned that they gave information. PSs distinguished the type of information that they provided—focused on daily struggles with diabetes management and personal problems</p> <p>Moreover, rather than addressing the technical challenges of peers' lives that could be easily addressed by experts (eg, medication dosage), PSs reported providing assistance for the adaptive challenges related to ongoing, evolving difficulties associated with diabetes management, such as ways to eat healthy or maintain exercise routines.</p> <p>Providing information was also a way of reinforcing peer empowerment; gaining trust to establish relationships with peers, particularly in the beginning of peer contact; and alleviating people's anxieties, fears, and stressors</p> <p>verbal discussion of peers' problems and contexts.³</p> <p>In defining emotional support, PSs from all sites described "just being there" for peers "I give them a hug. I can see that if they don't want to open up, I give them a big smile and let them know that I'm here for you."</p> <p>in the UK, PSs discussed how they went to a peer's art showing, organized walking trips, and played cribbage with their peers to build mutual relationships. PSs reported even being able to show implicit support over the phone—for example, PSs in North Carolina gave examples of talking about personal interests and family lives in a way that conveyed care and understanding.</p> <p>in particular, PSs from Chicago reported providing directive advice,³⁸ and PSs often described telling peers what they should or should not be doing</p> <p>"I tell them that they need to take care of themselves before taking care of others. I tell them, first, take care of yourself; second take care of your children."</p> <p>Similarly, in North Carolina, PSs frequently mentioned that it was not their position to tell a peer what they should or should not be doing; instead, they viewed their role as assisting peers in setting mutually decided goals.</p> <p>For instance, after careful discussion with peers, PSs in Chicago sometimes reported intervening with peers' family members by counseling them on appropriate support systems.</p> <p>PSs in North Carolina reported intervening with the community by providing linkages to community resources (eg, food pantries), community events (eg, wellness fairs), and helpful individuals (eg, pastors).</p>
<p>EM15 Taylor, Francesca et al. - 2016</p>	<p>networks did not meet all their needs</p> <p>To learn, share experiences, you know, get an idea of what's coming up next. What should I expect, you know, if I encounter a problem?</p> <p>Feelings of acceptance and understanding were also important benefits associated with peer support</p> <p>shared emotional experiences providing the reassurance and comfort of not being alone.</p> <p>wanted affirmation of the normality of their own experiences.</p> <p>Talk to other people and see whether they're moving roughly down the same route that you are, or whether you are just, well whether you're better or worse, you know. It's just a matter of trying to think well is everything normal y</p> <p>Participants were also keen to make active comparisons with others in a similar position, to compare positively upwards not downwards</p> <p>Respondents wanted vicarious encouragement that improvements were possible, and a role model, not someone imbued with pity.</p> <p>Not because the medics are bad or anything, it's just because they've just not walked that journey in the same way. They've sort of walked along-side you and are more observing, whereas this is more living it. (Patient 7)</p> <p>Talking to a patient or carer peer was considered a very different type of discussion to that between patient/carer and clinician. The latter was characterized as being more hierarchical and clinician-led; conversations tending to be predominantly medical focused. By contrast, peer support discussions were viewed as less constrained and more between equals.</p>

	<p>There was less of a clinical perspective with more emphasis given to emotional, practical and lifestyle issues. The language used between peers was also viewed as different, discussions being more in layperson's terms.</p> <p>The value and relevance of formal peer support was not viewed as time specific. There appeared to be different 'occasions' across time</p> <p>A number of participants, in particular patients dialysing at home for several months, and their carers, intimated they would be more comfortable being the provider rather than the recipient of support; the role of helper was both more familiar and more attractive</p> <p>many participants considered reciprocity and mutuality as key to encouraging their participation and important in preserving their dignity and self-esteem.</p> <p>I can accept it on an equal basis. I can offer somebody support and I can accept their support emotionally, I can deal with that. But for me to need support, emotional support, and not give anything back would be very hard. (Patient 5)</p> <p>Establishing good rapport</p> <p>rapport was closely aligned with creating the safe, trusting and empathetic 'place' where sharing and exchange could take place; the right emotional context for honesty and disclosure,</p> <p>I think you always want to make that contact with someone before you trust. (Carer 6)</p> <p>If you build up like a rapport with people I could probably tell them things, how I'm feeling, that I don't want to burden (carer) with. (Patient 3)</p> <p>A small number of interviewees felt similar socio-economic circumstances were important</p> <p>qualities needed were considered more personal attributes such as manner, presentation, sensitivity and communication style, rather than clearly definable skills or competencies</p> <p>the 'right person' with whom they could establish rapport might vary over time, depending on their emotional and physical states, and particular needs.</p> <p>At least some face-to-face contact was widely perceived to be necessary for rapport to be established</p> <p>Having choice and control in relation to certain aspects of the timing and delivery of formal peer support were important considerations for some interviewees.</p>
EN02 Browne, Annette J. et al. - 2012	<p>improved 'fit' between people's needs and service</p> <p>enhanced trust and engagement</p> <p>wellness programs.</p>
EN04 Cook, Catherine - 2012	<p>not everyone can get to a local support group or to their doctors/health clinic to talk to anyone if they have a problem or a question</p>
EN05 Graffigna, Guendalina et al. - 2014	<p>It would be nice to have dedicated spaces in which to meet with other patients to do activities together. Like cooking classes or physical activity programs.</p>
EN07 Hout, Marie Claire Van et al. - 2012	<p>I think it's a good idea. It will help my clients, if they decide to engage</p> <p>I think it is great and very useful. It gives a customer's perspective, valid and important .</p> <p>It has the potential for serious lobbying position if managed correctly</p> <p>organized groups such as the Mental Health Dialogues, Family Support Networks, Alcoholics Anonymous (AA)/Narcotics Anonymous (NA) and other self-help organizations could help link individuals to service user forums:</p> <p>really feel good to help other people, give all the options,</p> <p>support and meet other people in the same situation,</p>
EN08 Carlisle, Karen et al. - 2017	<p>scarce commentary on the inclusiveness and representativeness of communities</p>
EN09 Flournoy, Minnjuan W. - 2011	<p>this program was able to fulfill an unmet need within this population, but had concerns about continuous engagement in services if patients thought that there was a chance that the program would decrease services,</p>

EN18 Mitchell-Brown, Fay et al. - 2017



together to help encourage each other and to give advice about what they have done to help themselves fight diabetes. It's like learning from each other and using each other's ideas. the group helped me maintain normal blood sugar. They taught me to check my blood sugar and eat good foods.

EN19 Garcia, Jonathan et al. - 2015

safe spaces
 environment free of the stigma and discrimination
 social support, leisure-time and recreational activities
 safe spaces created a community of people who could provide mutual social support and organize activities
 A safe space
 safe spaces enabled discussions about public health messages related to black male sexuality, perceived HIV risk, and perceptions about being socially targeted as dangerous
 participating in peer-led groups (e.g., brotherhoods), leisure-time activity, and skill-building exercises in dedicated safe spaces can affect men's self-worth and their sense of belonging to ("being a part of") a community.
 We do training, as in we do exercises, team building, skill building. We learn how to work together as a singing group

EN28 Safo, Stella et al. - 2016

Reasons for joining the CAB included being asked to do so by research faculty, wanting to stay informed about HIV activities in the community, wanting to represent the community, and wanting to network with Bronx-based individuals working on HIV prevention and treatment efforts.

EN33 McDonald, Ruth et al. - 2008

I think in a lot of ways, you tend to know with people who are, they, they will ask you questions ... they're very, very, they're very interested and want to, they want to know more.

EN34 Natale, Anthony P. - 2009

Develop groups and workshops. Safe sex workshops are what I am looking for, for my partner and I. We want to learn more information about safe sex and we can't get it. a desire to participate in social- support and health-promotion opportunities designed for MSM
 strong preference for social support from others with HIV, and in kind expressed interest in providing support
 cultural sensitivity and relevance in HIV prevention
 importance of bilingual programs and messages.
 men also requested that staff members of prevention programs be representative of Latinos in order to foster greater utility
 I also think that somehow you need to reach Latino families. For Latinos your first responsibility is to your family, then your friends, then maybe you, or your career then you. So if you educate the families, they will educate the individuals.
 being able to make health linkages there

EN37 McCabe, Catherine et al. - 2014

I set up a support group and from meeting those people at the support groups and I helped with a few support groups now and that gives me a sense of purpose or reason to do thing

EN39 Durme, Thérèse Van et al. - 2014

The education role by nurses is enhanced by the work of patient associations

EN42 Fairbrother, Peter et al. - 2013	Professionals outlined the importance of formalized self-management training and support to engender medically compliant attitudes and behaviors in patients.
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Table 14 -Recommendations for implementing and conducting health education

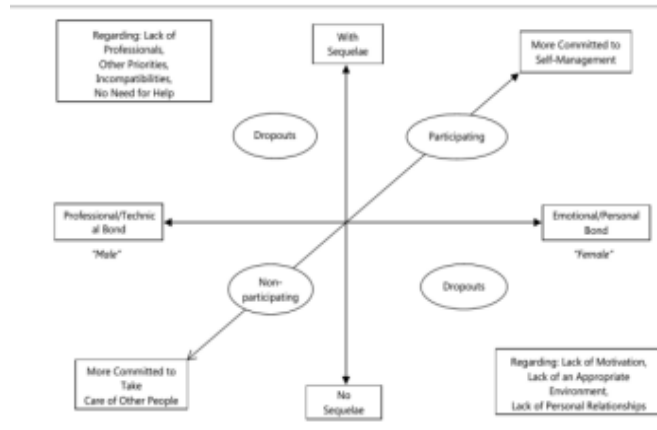
CO33 Vilhauer, Ruvanee P. - 2014	<p>can take place on your own terms</p> <p>a CMSG affords more opportunity for getting to know others intimately than does a FTFG, it's just different by virtue of the face-to-face versus you know, not seeing, not having a picture of these ladies in the e-mail group. And yet, we do maybe, probably know them more intimately. The e-mail support group people more intimately ... It's just a different kind of knowing."</p> <p>more frequent communication</p> <p>the opportunity to discuss more details</p> <p>a face to face group, when you meet somebody you can receive their body language</p> <p>occasional meetings or reunions might have accelerated the development of intimacy in the CMSGs, and one suggested that swapping of photographs might have done so.</p> <p>they were able to express themselves better in a CMSG</p> <p>"...Email allows us all to hide out, so to speak, for lack of a better explanation." Members could express their thoughts more clearly and with fewer concerns about saying the wrong thing because they had time to consider and revise what they had written.</p> <p>you can stop and think about what you want to say next, or let the thoughts and feelings come in</p> <p>you don't necessarily have to be as spontaneous</p> <p>the absence of an interlocutor who might interrupt the flow of thought</p> <p>So you stay focused, momentarily, on wherever you are</p> <p>Having a facilitator may also promote honest communication in CMSGs</p> <p>When painful topics are introduced into CMSG discussions, these can remain unaddressed because of the nature of e-mail interaction</p> <p>the presence of a facilitator might have addressed this problem and promoted healthier communication among group members</p> <p>The presence of a facilitator might have helped to alleviate any discomfort experienced by those who were unsure, because of the absence of nonverbal cues, about the appropriateness of broaching difficult subjects.</p> <p>A facilitator might also have helped to alleviate the anxiety that can arise when members stop writing to a CMSG</p>
CO35 Goddu, Anna P. et al. - 2015	<p>Most participants liked sharing their personal stories. Several reported feeling initially unwilling to share, but becoming more expressive throughout the DEP</p> <p>Participants felt that sharing and hearing personal stories enabled learning in an experiential way</p> <p>storytelling promoted social support, decreased participants' sense of isolation, and relieved stress.</p> <p>boosted their self-confidence and motivated behavior change</p> <p>participants' reported initial response to role-playing (from shy reluctance to enthusiastic participation), although the majority were receptive. Over time, with experience and continued exposure,</p> <p>Participants reported being transported by the use of narrative in the DEP, particularly in regards to the film. Being transported into the stories portrayed in the film and by their classmates created an enjoyable experience and made the messages believable</p> <p>seeing was believing</p> <p>Participants identified with the characters and events in the film, and also with each other's stories.</p> <p>the social proliferation of the narratives in the DEP - watching and discussing the film in a group, sharing personal stories with each other, and role-playing as a group - had an impact on their behavior change</p> <p>rehearsing the behaviors,through role-play or through discussion of stories in which behaviors are modeled, reportedly increased self- efficacy, disseminated practical strategies, and facilitated skills training in the self-managementtechniques introduced in the class.</p>

	I felt like a brick was removed from off of my head because I was able to share what I was feeling. ... They didn't interrupt me or nothing
ED10 Costello, Joanne F. - 2013	<p>for successfully running this type of group is "that they always feel like equals, everybody needs to feel equal."</p> <p>understanding of the connection of diabetes to all aspects of the life of the individual w</p> <p>They'll talk about their son-in-law who's got diagnosed with cancer and they'll go on and on about that and then that gives me the opportunity to say, 'How has that stress affected your ability to cope with your diabetes, or your blood sugars? Have you noticed your blood sugars are out of control?'</p> <p>facilitator strategy of connecting, which includes connecting within the group as well as connecting group members with community resourc</p> <p>"I strive for a connectedness. I really believe that humans are striving to be connected with one another. We're in this together, we're going to come to solutions together.</p> <p>Exchanging information involved sharing, interpreting, and applying information to daily life, correcting misinformation, and selective, goal-oriented facilitator self-disclosure.</p> <p>Creating the environment</p> <ul style="list-style-type: none"> • making a safe place • attending to the space • fostering a positive milieu <p>Coordinating flow</p> <ul style="list-style-type: none"> • coordinating flow • pulling in quiet members • toning down gregarious members • dealing with a negative presence <p>Fostering group roles</p> <ul style="list-style-type: none"> • enabling peer mentoring • pulling together member strengths and needs • developing the group member cast • holding back to allow for group development <p>Self-disclosure as a form of information sharing was identified as a strategy to be used only selectively to further goals of the participants.</p> <p>creating the environment, including making a safe place</p> <p>coordinating flow, including filtering out problems not appropriate for group intervention, engaging quiet members in the discussions and toning down gregarious members, and dealing with a negative presence;</p> <p>Fostering group roles,</p> <p>enabling peer mentoring</p> <p>holding back to allow for group and group member development</p> <p>Being a catalyst for the development of problem-solving skills was the fourth identified strateg</p>
ED12 Caine, Vera et al. - 2016	<p>both nurse mentors and mentees valued PLWH mentor openness, courage, and sharing of life experiences</p> <p>the research team conceptualized the intervention to be identical at each site. Over time we realized this was not feasible and that the delivery of the intervention was impacted by attitudes of nurse and PLWH mentors, mentees, and the sociopolitical nature of HIV care i</p>
ED14 Vega, Gema et al. - 2014	<p>Hence, to learn the potential profiles of participating and nonparticipating patients, as well as those of drop-outs, it was necessary to keep their baseline stances in mind. Suchstances could be graphically illustrated in a coordinate diagram (see Figure 2) in which the main axes are defined by the degree of sequelae (with or without) and the care preferences they requested (more technological and professional [male component], or more personal and human [female component]). N</p> <p>the information on these dimensions distinguished patients who prioritized care/support of other people over themselves from those who focused on their own care needs</p> <p>Particularly in the evening, because in the morning we are babysitting</p> <p>I have always read that work is secondary. First comes health, and your job is what you can do afterwards. It's that, it's that your job, it's not about the job. Your job is, it's your</p>

mortgage, and this and that. So, if you don't, if you don't work, you can't, can't move on with your life

The thing is my kid [child] doesn't need one of us, but two, then, since we have the stationery shop, since that's how we are.

The difference in patient priorities (self-care or care of others) determined the degree of participation in the EPP.



3. Degree of participation in the Expert Patients Program, depending on patient context.

ED15
Goebbels,
Adrienne F. G.
et al. - 2012
ED15
Goebbels,
Adrienne F. G.
et al. - 2012

The counselling sessions provided the opportunity to discuss progress with LBC on a regular basis. This motivated respondents to continue with lifestyle changes. S

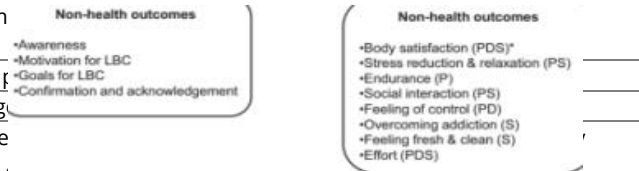
A possible way to improve the potential of the counselling to increase participants' motivation for LBC was also discussed. Several respondents had the expectation that the results of the physical measurements conducted during the HPS (i.e. anthropometric measurements, blood pressure and blood tests) would be addressed during the counselling

Incorporating regular monitoring of the impact of LBC on physical indicators of health risks was suggested as a way to improve LBC.

participants appreciated the confirmation and acknowledgment

"Well, in the sense that you've achieved something, that it is

The dividing line between the non-health and health outcomes was however not always clear-cut.



ED16 **Wright,**
Nicola - 2013

Accessibility

how they found out information and were referred onto the courses available locally and the amount of travelling they had to do to attend it
accessibility in terms of the material presented
enough material presented at different levels

the standards of different courses and the standards of different people vary so much. I am someone who is fairly well academically qualified and I found a lot of it very very basic but then on the other hand a few of the things you pick up can be totally life changing

accessibility of ongoing support after the self-management courses had finished was an issue for all the participants.

The use of online forums was raised as a potential solution for both the accessibility issues relating to the self-management courses and also the provision of ongoing support afterwards

What's the possibility of doing something online? To overcome communication and practical problems, people could then have stuff going into their own homes (004 FG1).

	<p>I did belong to a depression group on the internet but you can't beat meeting people face to face</p> <p>Being isolated reduced a participant's ability to implement the techniques they had learnt after the course had finished.</p> <p>I am of the view that the courses are only as good as the people going and I gained a friend and we have stayed in touch and we go out for coffee and discuss our problems and that was the main benefit for me. It is how people make you feel; you never forget how people make you feel.</p> <p>The short-term nature of the programmes did not in some cases facilitate the building of trust to make the necessary self-disclosures. Whilst participants were disappointed at the lack of signposting to other services at the end of the programmes, the majority did not feel able to set up their own groups to maintain the social support and networks which had developed through attendance at the course.</p> <p>Maintaining the positive reframing of their experiences was difficult for participants after the course had finished. As highlighted previously, the return to isolation and a lack of structure or purpose in life once again led to individuals feeling devalued and in some cases behaving in very destructive ways</p>
ED2 Barlow, J. H. et al. - 2009	<p>valued the interactive and experiential nature of the EPP</p> <p>motivation and techniques to translate the advice received into positive behaviour change</p> <p>valued the goal setting, mutual support within the group and support from tutors</p> <p>coping</p> <p>described the 'spirit' of the EPP as friendly, uplifting and positive</p>
ED4 Blixen, Carol et al. - 2015	<p>Build a group culture that facilitates easy sharing, disclosure, and integrates viewpoints from different personalities</p> <p>Setting the stage—Setting the stage for the group training is an important first step in establishing group cohesiveness. This means striking a balance between having enough people to add to the discussion and not having so many people that some feel left out.</p> <p>Groups of 6–10 facilitate group cohesiveness</p> <p>"I loved the snacks. I think they were a good idea because all of us are diabetics and sometimes being a diabetic you need a snack at that time of day. But they give us things that are wholesome and nutritious, and we learned that there are things that you can eat that are good for you</p> <p>can go have your coffee and your snacks as you learn,</p> <p>Set ground rules that will allay fears about unwelcome disclosure or betrayal of boundaries</p> <p>requesting PE's attendance</p> <p>promptness</p> <p>positive and constructive as well as non-judgmental and encouraging</p> <p>not to share any personal information about group members outside of the group.</p> <p>Setting rules for group behavior—Encouraging one person to talk at a time, showing courtesy and respect to others, and acknowledging and accepting differences while establishing a sense of trust</p> <p>everybody treated me with courtesy and respect</p> <p>on-going training is intensive and supportive enough to build confidence</p> <p>"Nurse Educator X in the TTIM group I was co-leading was fabulous in teaching and then after class we may have a couple words and she always encouraged me, I'm working on being the best."</p> <p>reviewed certain chapters and sections of the manual with the group, answered questions, and facilitated discussion of the contents.</p> <p>Promote peer educator innovation</p> <p>written handouts and homework</p> <p>Reinforce peer educator role and role limits, rules for dealing with crisis or unexpected situations</p>

	<p>To minimize logistic/scheduling obstacles, training sessions were held at a consistent day/ time and last no more than one hour</p> <p>Emphasize and re-enforce the notion that participants are “United in Purpose”</p> <p>cultivating the telos of a group is fundamentally important to success in training PE’s to deliver health promoting interventions.</p> <p>Basically, it’s to encourage everybody to feel confident in themselves, that they can control their diabetes and mental illness. S</p> <p>We just want them to feel comfortable and feel encouraged and, empowered. We’re trying to empower everybody. J</p>
ED5 Albarran, Cynthia R. et al. - 2014	<p>‘the panchita obligated me to go out, because I had to put it on so they [promotoras] can see that I did walk. So that was helpful for me.’ She discovered that she liked the panchita and as a result, she ‘began to feel good</p> <p>health assessments to check blood pressure, lipids and glucose at baseline plus 6 and 9 month follow-up</p> <p>These health assessments enabled them to track their progress and identify the other lifestyle changes that were needed.</p> <p>Because promotoras were seen as women with whom participants could identify, the women paid special attention to promotora’s actions and behaviours, and their personal qualities.</p> <p>The women were inspired when promotoras displayed enthusiasm in both teaching classes and modelling healthy behaviours.</p> <p>promotoras when they were held accountable for their efforts</p> <p>dynamic of personal recognition of their hard efforts. P</p> <p>Promotoras also were perceived as counsellors from whom participants wanted emotional support.</p> <p>sensitive to the mental health needs.</p> <p>Women wished that mental health information and support would be an official part of the curriculum and the promotora training.</p> <p>promotoras fostered a sense of companerismo ~ (companionship) that was shared among many women in the programme</p> <p>Women expressed desire to exercise in groups to increase motivation. Some suggested that a future group dance class would be a fun way to exercise with other women.</p> <p>Promotoras were thought to have several personal qualities that were desirable and motivating such as being patient, trustworthy, friendly, determined and caring.</p> <p>Participants valued their experiences of learning through videos and role playing (skits). Watching and participating in these productions motivated women and inspired them with the desire to avoid illness</p> <p>By acting out a scenario about a person who was at risk for a heart attack and then discussing the experience with a promotora and her peers</p> <p>Another way that knowledge was infused (both as product and process) was through informational brochures given out by promotoras.</p> <p>. Height and weight charts, portion size diagrams and informational tips on topics such as how to listen to your body and how to know when you are hungry/full were perceived as helpful and inspiring.</p> <p>women wanted more of each component: more tools, more support and more knowledge</p> <p>their promotoras pre- pared food in class or brought samples of healthy foods to taste</p> <p>more contact with promotoras such as greater frequency of phone calls and home visits. Women said they wanted more ‘constant’ support from promotoras because it would nurture more motivation, which would then lead to a greater ability for her to change.</p> <p>Women also wanted the promotoras to facilitate communication between participants; they reported sadness over losing contact with their peers after the conclusion of the programme</p> <p>the program format should facilitate fellowship and cultivate a sense of “brotherhood”</p>

ED7 Hurt, Tera R. et al. - 2015	<p>Facilitators should have the positive intention of serving others (e.g., no representatives from self-interest groups) and should be sure to view program participants as their equals and avoid “talking down” to them.</p> <p>the material should not be too complicated; otherwise, men will not actively participate and return for follow-up session</p> <p>The sessions should rather be “interactive, informative, quick, and powerful.”</p> <p>The overarching framework for the program should be one of empowerment and recognition that there are consequences for choices individuals make regarding their health (</p> <p>men suggested that the program should next cover diet alternatives for diet and physical activity, taking into account busy schedules and limited resources</p> <p>(e.g., “In trying to maximize my time, I often compromise the quality of the food I eat.”)</p> <p>Each session should provide the men with something tangible to be applied in their daily lives</p> <p>Some men advised that the program be held at various locations to appeal to different people. One man said, “People feel ‘safe’ in different locations of the city.”</p>
ED8 Sekse, Ragnhild Johanne Tveit et al. - 2014	<p>To open up and share my fundamental feelings in relation to my cancer experiences</p> <p>Differences in age and in the individual’s situation in relation to diagnosis, intervention and consequences for lived life did not seem to have great impact on recognition and understanding.</p> <p>Others spoke of a feeling of recognition on receiving information and counselling that helped them give words to their knowledge of the altered body, a knowledge they already possessed physically</p> <p>coping and the strategies used.</p> <p>caring and trusting environment for sharing experiences was essential</p> <p>focus on positive coping strategies</p> <p>teaching the women to handle and communicate about challenging and vulnerable topics</p> <p>The women underscored the importance of the groups being led by skilled health professionals. Mary said: I don’t think the outcome would have been the same if we had just sat and talked with each other [without nurses]... That would have been more of a self-pitying group.</p> <p>The participation of healthcare professionals and their focus on coping and coping strategies, within safe and clear boundaries, were expressed as important for a positive outcome.</p> <p>healthcare professionals’ contribution was the opportunity for dialogue with them, as well as with the invited speakers</p> <p>I think it is a privilege, in this group, that we can sit here with a doctor and ask questions...</p>
EM02 Miller, Robin Lin et al. - 2012	<p>“Our goal [is] to impact them as it relates to not just the epidemic but life in general” – YBU Member</p> <p>developing young men’s leadership skills and personal potential</p> <p>The program now mirrors structures that promote the development of civic and service-minded citizens: family, church, school, fraternity.</p> <p>Food and prayer play a central role in cementing a familial bond among the young men and making the space a second home</p> <p>The regard for the organization as a safe space in which young men can find social and material support to realize their potential in life, learn to protect their selves sexually, and feel at home was articulated consistently</p> <p>The severity of the epidemic in Detroit limits the degree to which empowerment Detroit is willing to rely on an informal peer-based approach to normative change. Peers remain central to the program, but are deployed to engage in conventional forms of outreach, HIV prevention education, and linkage to testing and care and only after intensive preparatory training.</p> <p>Members believe outreach by trained professionals who can conduct risk assessments and testing is optimal and better supported by evidence than the outreach approach in the original model</p>

	<p>professionalism during outreach was important because members do not want to “set a bad example” when out in the community.</p> <p>members emphasize the role the Sunday sessions play in addressing the diversity of needs, issues, and concerns facing young black gay and bisexual men. Although creating Sunday sessions offers opportunities for members to participate actively in the project’s programming, greater emphasis is placed on planning and facilitating as an active learning occasion for those who have earned the privilege to plan and facilitate.</p> <p>ther services are available to those attending, such as onsite HIV testing provided by agencies</p> <p>with which Mpowerment Detroit has collaborative partnerships.</p>
<p>EM05 Oliffe, John L. et al. - 2008</p>	<p>group leaders had to have the capacity to manage the organization and promotion of group meetings.</p> <p>leadership committees that met regularly to plan group meetings, which they actively promoted by tele- phoning and e-mailing members. Leaders were also responsible for recruiting speakers. Because the leaders from groups 3 and 7 had strong linkages to doctors who specialized in prostate cancer, these groups benefited from having ready access to expert speakers.</p> <p>ability of the group leaders to engage new members and establish rapport and a prevailing sense of camaraderie</p> <p>The majority of first-time attendees were newly diagnosed men, and specific strategies were used by some groups to welcome new members. For example, at group 4, one leader welcomed and invited new members to raise their hands at the beginning of the meeting and another designated leader formally greeted the six first-time attendees, all of whom were newly diagnosed, to discuss various treatments for more than an hour after the official meeting. Similarly, the leader of group 13 talked with new members (in this particular case, men and their wives) during the refreshment break and at the conclusion of the formal meeting</p> <p>new members were explicitly included, given permission and opportunity to talk, ask questions, and receive the information they required</p> <p>offer “new” information to maintain the interest of long-term members,</p> <p>access to health care professionals willing to formally present prostate cancer and health information. For example, oncologists explained brachytherapy and HiFu radiation at group meetings, and the presentations drew on current research and clinical practice</p> <p>current of empowerment and building individual group identities</p> <p>to promote awareness, conduct fund-raising events, and contribute financial support to prostate cancer research.</p> <p>the work of PCSGs is unpaid, and there was widespread reluctance to work for (or to be perceived as working for)</p> <p>ather than with professional organizations</p>
<p>EM10 Peterson, Jennifer L. et al. - 2012</p>	<p>Yes, they [an ASO] have a buddy system and my friend David just left. He moved to Dallas, so I have to find another buddy. But we do everything together, we go out together, we go out to eat, go to the movies, go to each other’s houses, work on the Internet, and different things like that.</p>
<p>EM15 Taylor, Francesca et al. - 2016</p>	<p>advantages of learning practical adaptive coping skill</p> <p>Other participants talked enthusiastically about gaining knowledge about how to address particular personal issues in relation to their illness and treatment. General everyday things, sex and things like that... find out if they’ve been in that situation. (Carer 6)</p> <p>Validation of personal feelings and behaviour</p> <p>greater choice, control and ownership</p> <p>Being able to take a key role in choosing their own peer supporter/s was viewed as especially important,</p> <p>Preferences for the format and delivery of formal peer support varied considerably, and there was a strong desire for choice.</p> <p>Different people need different things at different times. (Patient 15)</p>

EM17 DiGiacomo, M. et al. - 2015	<p>A local women's-only health facility was perceived as a safe space. This facility did not allow men into its premises and did not allow husbands, boyfriends, or children to accompany women.</p> <p>"So it was a – a man free place. And that made a huge difference, you know, because a lot of women who came there were women who'd been beaten up by men...We got a lot of those, although we weren't funded for domestic violence – that didn't stop women coming in, you know, bruised and beaten and asking for help...Especially in that area, but probably all over the [this region]." (CM)</p> <p>For example, older women living alone in the community are often overlooked service-wise. "If women have a good group around them, like neighbours and friends that will help. It doesn't have to be a big group, just some key important people that, ah - all women should look out for them that way, that's this mutual thing." (PS)</p> <p>"Just by the nature of the way women, and the strengths that women have, I think that I've seen in the CALD communities, women use the verbal; they - they want word of mouth, they have trust amongst their informal networks." (PS)</p>
EN01 Ekundayo, Olugbemiga T. et al. - 2012	<ul style="list-style-type: none"> • family members involved, or • someone close to us are going through it <p>Engaging prostate cancer survivors and community members</p> <p>Have spokes persons to come and present it</p> <p>celebrities</p> <p>Rap videos about the prostate cancer</p> <p>Cultural Competence</p> <p>Dissemination format and context</p> <p>Community problem prioritization</p> <p>survivors</p> <p>prostate Cancer survivors</p>
EN02 Browne, Annette J. et al. - 2012	<p>participatory engagement of patients, and is fostered by adopting clinic structures that encourage 'patient activation</p> <p>Tailor care, programs and services to the context of people's lives (e.g., cultural, social, gender, and demographic contexts)</p> <p>Create opportunities to promote and foster engagement with community and other sectors, including participatory engagement by patients</p> <p>involve engagement and collaboration with various sectors in the local community and beyond to maximize opportunities to address the social contexts of patients' lives</p> <p>action at the level of policy</p> <p>peer support programs. These experiences offer powerful points of connection for people marginalized by social and structural inequities</p> <p>wellness programs.</p> <p>hire patients as peer interviewers and research assistants</p> <p>Engaging in meaningful work-related activities through volunteer and temporary or occasional employment opportunities can be health promoting by enhancing people's sense of self-efficacy, self-worth, and capacity to manage their health</p> <p>Tailor care, programs and services to the populations' individual and group histories, with an emphasis on trauma- and violence-informed care</p>
EN07 Hout, Marie Claire Van et al. - 2012	<p>Satellite service user forums outside of XXXX [city]. Rural clients see the service as city-based and not for them.</p> <p>need for more resources to be allocated for forum facilitators (i.e. laptops, room rental), recruiting SUST representatives and identifying leaders who have the potential to engage service users (</p> <p>You need to provide mobile credit and internet access... Host the forum once a month in XXXX [city]</p> <p>utilization of internet forums to advertise the service user forums. I</p> <p>maintain client anonymity</p>
EN08 Carlisle, Karen et al. - 2017	<p>different people, from different organisations to come together and brainstorm ideas around what things could be implemented in the community</p> <p>e one to one conversations are incredibly valuable</p> <p>make those connections with people." [E</p>

	<p>focused on groups they perceived needed more support or within an area they were working in and could incorporate into their existing work,</p> <p>in fact, maybe even at, the schools run a skills thing where people come and they have a look at where they might like to get jobs in the future,</p> <p>integrating program-related workshops with existing community meetings increased the numbers of people contributing to the process during both planning and implementing phases</p> <p>more embedded into existing community structures, the more likely it was for community members to take responsibility for monitoring the implementation of oral health plans.</p> <p>we having the community advisory network engaged in the process I think we probably, if they weren't involved then I don't think we quite would have had such a good outcome."</p> <p>working on low cost sustainable ideas</p>
EN14 Hirjaba, Marina et al. - 2015	family, other patients with diabetes and the local Diabetes Union
EN18 Mitchell-Brown, Fay et al. - 2017	<p>physical accessibility</p> <p>Cost</p> <p>diabetes education should be taught with the consideration of their literacy level and culture. T</p> <p>a program focused on diabetes education and offered in Hmong too</p> <p>I would like you (researcher) to take pictures of fruits, grains, or any foods, that way I see it, because I cannot read it</p> <p>Culturally appropriate education is a gold standard in providing diabetes education in ethnic minority groups because it has the potential for significant improvement in diabetes knowledge and management.</p> <p>use of pictograph and videos.</p> <p>Pa'ndau is a pictograph that is specific to the Hmong culture and can be used as a tool to educate the Hmong about medical concepts and terminology u</p> <p>watching a movie would best facilitate diabetes education b</p> <p>Using visual and oral communication is consistent with Hmong tradition of watch-ing and listening and a rich oral storytelling tradition</p>
	<div style="display: flex; justify-content: space-around; align-items: center;"> <div style="border: 1px solid black; padding: 5px; background-color: #333; color: white; text-align: center;"> <p>INTERVENTION TARGETS</p> <p>Culturally Appropriate Education</p> <p>Use of videos and pictographs to provide education</p> <p>Provide Education in Hmong Language</p> <p>Reduce Stress</p> </div> <div style="border: 1px solid black; padding: 5px; background-color: #333; color: white;"> <p>DIABETES EDUCATION EXPERIENCE</p> <p>PERCEIVED FACILIATORS</p> <ul style="list-style-type: none"> • Focused • Culturally Specific • Education • Pictograph • Video • Peer Support Group <p>PERCEIVED BARRIERS</p> <ul style="list-style-type: none"> • Language • Self-Management • Stress </div> </div>
EN19 Garcia, Jonathan et al. - 2015	<p>We need to meet in a group with the same health condition t</p> <p>we observed at several other HIV CBOs used "art therapy" to address emotional situations.</p> <p>polycymaking</p> <p>capacity building to sustain safe spaces a</p>

EN25 Robinson, Nicola et al. - 2015	<p>More meaningful engagement methods were thought to provide ownership, byempowering individuals</p> <p>Flexibility</p> <p>Organizational commitment</p> <p>Who is engaged – motivating patients/public, especially disadvantaged and ‘at risk’ communities rather than vocal/activists</p>
EN34 Natale, Anthony P. - 2009	<p>I think we need to have support groups around addictions—sexual ad- dictions and drug addictions. They need to be specific support groups for gay men who use drugs developed for them with their needs in mind.</p> <p>raised within the context of community centers that focus on the needs of MSM a peer mentor system</p> <p>I also would like to see something like self-esteem enhancement, maybe classes that you can take.</p> <p>Given the ethnic and racial, age, income, and HIV status diversity</p> <p>social supports designed for MSM subgroups be relevant to each group</p> <p>interpersonal skill development as central to in- creasing sexual negotiation</p> <p>I am not sure how you would do this, but education on the Internet would help.</p> <p>partnering with education institution</p> <p>cultural sensitivity and relevance in HIV prevention</p> <p>Bilingual information is important</p> <p>enhanced racial identity</p>
EN35 Gien, Lan et al. - 2017	<p>a peer support group, but also stressed having a professional to provide accurate DM information</p>

Table 15 - Barriers for implementing health education programmes

CO08 Dowling, Joni E. - 2010	<p>She did not pursue attending the support group because the group met on a weeknight</p> <p>the hospital was located too far from her home.</p> <p>felt like a minority as one of the few young women in the group</p> <p>figured the women participating in the group were not her age attending were much older.</p>
CO33 Vilhauer, Ruvanee P. - 2014	<p>Women who lived in rural areas with- out easy access to FTFGs</p> <p>women who had difficulty attending FTFGs because of illness symptoms or treatment side effects</p> <p>She found reading the messages from other members time-consuming.</p> <p>busy</p> <p>her lack of computer literacy</p> <p>it took me so long to read the mail, that by the time it came for me to write, I was too tired to write</p> <p>time is limited in a FTFG that meets weekly or bi- weekly, not all members have a chance to broach issues that are troubling them.</p> <p>Time</p> <p>if somebody comes in with major bad news, like you know, they got really bad scan results, and their disease is progressing aggressively, then there is a sense that the group time is going to be devoted to that person. And other people feel then, oh well, what I have to talk about is irrelevant or not as important.</p> <p>a FTFG, because of the limited time available, there is less opportunity for members to discuss non-illness related aspects of their lives.</p> <p>The three women attributed the reduced intimacy to lack of physical presence</p> <p>Probably just because I am a people person, coming in contact with them directly rather than just typing,</p> <p>It was very, almost mundane to me</p> <p>it took longer for intimacy to develop in their CMSGs</p> <p>the absence of visual cues</p> <p>the absence of immediate interaction can impede communication by diffusing focus.</p>

	<p>When you're writing, you can't say as much as when you're sitting there going back and forth, responding immediately to one another</p> <p>However, CMSGs may also prevent women from addressing fears when they are ready to do so. Women who have come to terms with the possibility of dying from the disease need a venue to talk about this subject, which often weighs heavily upon their minds.</p> <p>Six interviewees mentioned that questions asked sometimes did not get answered in the groups.</p> <p>Declining participation in an un-moderated CMSG has the potential for snowballing because members, not knowing why others are writing less to the group, might attribute motives of disinterest or lack of attachment to them</p>
ED10 Costello, Joanne F. - 2013	<p>perfection in diabetes self-management was neither possible nor desirable, best illustrated by a facilitator who also had lived with diabetes for 26 years. She described the overemphasis on adherence in diabetes education and the unrealistic expectations that it entails: [I]f you are perceived as perfect and you've got it all together, then that isn't helpful. I think that's another message that has to be said often in a group is this is not a perfect disease, nobody manages it perfectly, and you could become obsessive compulsive if you try and manage it perfectly.</p>
ED11 Dale, Jeremy et al. - 2008 ED11 Dale,	<p>Negative aspects of the telecare supporter role included difficulties associated with finding convenient times for calls, attempts needed to make a call, and for some patients, challenges with the call content (e.g. keeping people focused, resistance to setting goals and making changes)</p> <p>• No additional support was felt necessary: <i>- "It's a good idea but I've sort of got it all under control myself". (P6)</i> <i>- "I told them I was quite happy with everything. I think [my diabetes] will probably get worse but it's not good worrying about it now". (P8)</i></p> <p>What were the most challenging calls? • People who did not want to make any changes: <i>"I've put my name down because I have to do it. I have no problems." (P6)</i></p>
ED12 Caine, Vera et al. - 2016	<p>involving PLWH as mentors also proved challenging because few nurses had worked with PLWH in meaningful and relevant ways in their daily practice</p> <p>PLWH mentors faced personal health challenges or economic instability, which precipitated, at times, moving in and out of their roles as mentors</p> <p>Others faced challenges of role clarity and feelings of vulnerability</p> <p>Some public health nurses were puzzled by the need to prove that learning about HIV care was relevant to their work. As one mentee shared: "My manager just felt it wasn't directly applicable to my work, which is not correct; we're public health generalists out here, we are responsible for knowing about sexual health and communicable diseases" (Urban mentee). Yet in the same city, administrative gatekeepers considered that too much research related to HIV occurred at particular clinical sites and denied our request to access potentially interested nurses. After many months of communication with officials during the application process, the ethics officer gave us the final answer:</p>
ED15 Goebbels, Adrienne F. G. et al. - 2012	<p>Other respondents found the counselling useful, but they did not change their lifestyle behaviours.</p> <p>"Well, I have my experience. I had a conversation and it was nothing new actually. And then I stopped immediately in fact. It was a conversation and it was not worthwhile in my situation."</p> <p>respondents were only externally motivated, however. They felt the need to justify failure to progress with lifestyle changes otherwise</p> <p>not all participants were able to maintain motivation for LBC.</p> <p>Some respondents reported that they gained body weight due to LBC. They became less satisfied with their body. This happened mostly to people who stopped smoking and then started eating more unhealthy snacks,</p> <p>A negative consequence of LBC many respondents mentioned was the effort associated with it. F</p>

ED16 Wright, Nicola - 2013	<p>the time-limited nature of the courses had led to them feeling unable to implement and use the techniques they had learnt.</p> <p>With the course you feel it is everything and then it is nothing and you feel really let down. It was useful but now I have been cut loose and you lose motivation</p> <p>What you need is someone to talk to rather than shuffling through lots of bits of paper the majority of people did not maintain contact with others they had met. The end of the course meant a return to the isolation they had experienced prior to attending.</p> <p>There is nothing unless you can set up and run your own group. I ran a group for five years or so as a foreman. It is bloody hard work and you are expected to do it. I am all for my fellow man or woman and helping them, however you don't realise how much it takes out of you to set up a self help group (008 FG1).</p> <p>for others the EPP was perceived to lead to an individual becoming 'entrenched in the medical model': In the end I ran a mile from the EPP, you become entrenched in the medical model of disability when you have a sudden onset condition in later life, Doctors, Nurses, Physios.</p>
ED5 Albarran, Cynthia R. et al. - 2014	<p>women were frustrated when promotoras identified some topics as being beyond their scope, such as those related to medical management of hypertension and high cholesterol</p> <p>'Well, if they [the promotoras] don't want to say it, then bring a doctor. Bring a doctor and have him clear all doubts that everyone has.'</p> <p>participants were not satisfied with being referred back to their personal physicians, as many did not have a primary physician and felt more comfortable asking their questions in the programme environment.</p>
ED8 Sekse, Ragnhild Johanne Tveit et al. - 2014	<p>Some of the women were initially disappointed at being randomized to the education and counselling group intervention. Several of them had feared that such a group would be focused on negative problems.</p>
EM02 Miller, Robin Lin et al. - 2012	<p>"failing to speak to the young black man of today stereotyping of gay men, overly focused on middle-to-upper class lifestyles, and frivolous. not what we [blacks] perceive as a good time or a social activity".</p> <p>Young men were irritated by the questionnaires that are part of the session, complaining that the intervention included "too much paperwork.</p> <p>In addition, men balked at the white-sounding names and "flamboyant" portrayal of gay men.</p> <p>Role plays met with particular resistance acting out hypothetical situations.</p> <p>Although members said that they learned important things via the group, the style of the group was ill matched to young men's preferred ways of learning in groups and interacting with one another.</p>
EM05 Oliffe, John L. et al. - 2008	<p>the leadership of some groups fell entirely to one or two people, often for long periods of time, and this became a burden, especially for elderly men experiencing declining health.</p> <p>one leader was responsible for all aspects of the group, and although commended by group members, the leaders' repeated requests for others to take up leadership roles did not result in identification of successors. Sustainability was an issue in these groups, because no matter how strong in terms of the number of attendees, without leadership succession planning, the group was in jeopardy if the current leader stood down.</p> <p>workload responsibilities associated with sole leadership</p> <p>In terms of group sustainability, it is unclear if linkages to professional associations—such as that achieved by affiliating with a national, well-known, and respected cancer society—would ultimately benefit PCSGs.</p> <p>Formal linkages to professional organizations can enhance public perception of group legitimacy and expertise.</p> <p>Although most groups and their members were, by definition, advocates at the local level, disjunctures between the national vision for activism and the capacity of many groups existed. This left some groups vulnerable to collapse if their limited resources were redeployed from local to more global activist activities</p>

EM09 Grande, Stuart W. et al. - 2013	I couldn't share that with them because they're not black. . . so if they're not black I can't talk to them as if they are black . . . so if any one of them came up to me and said my nigger, I'd be ready to fight . . . because they don't know what we went through to say that word.
EM10 Peterson, Jennifer L. et al. - 2012	the online group allowed him to connect to people who he perceived to be similar to him, this participant did wish for the face-to-face contact that some (but not all) members of the group were able to experience. Well one-on-one versus a big group. You can get a lot more individual attention and focus on the one person. That voice can have a lot more control. It is always amazing how people will open up more in a one-on-one. They disclose more The one [friend] I do talk with I've known for a long time, he is HIV-positive, and he knows my ex who gave me this. So he and I talk a lot. I feel more comfortable with him than I would in a support group. N
EM11 Nota, Ingrid et al. - 2016	Patient lacks knowledge "Of course many decisions are made for you, because you yourself cannot... I did not know anything about this when it all started." [Female, 17 years]
EM12 Wiljer, David et al. - 2013	As many participants were satisfied with the amount of information regarding their health condition provided in the SC, some indicated that the SC would have been more useful to them if it was conducted at a different time in their cancer journey. There were a number of participants who had sufficient knowledge regarding their healthcare team, health condition and treatment options. These participants found the SC to be too repetitive and reported no change in their level of understanding
EM13 Kowitz, Sarah D. et al. - 2015	In the UK and North Carolina, explicit support was nondirective, as emphasized in training protocols. In fact, one of the difficulties discussed by PSs in the UK involved navigating their roles and communicating their "peerness" to participants. This included having to clarify with peers that they did not have the answers to peers' concerns (eg, correct medication dosages)
EM15 Taylor, Francesca et al. - 2016	Respondents explained how their emotional 'mood' or 'frame of mind' at particular points might inhibit or motivate response to a desire to talk with another patient or carer. ..Sometimes you just feel like I don't want to talk about it, I don't want to know...Sometimes it's you're overloaded with what's happening to you. (Patient 15) The individuality of the peer support 'occasion' was clearly evident. For example, some participants thought peer support would have been beneficial when they first received a diagnosis of kidney disease, to help reduce the inevitable uncertainties about their condition, its future course and effect on their life. Others felt too overwhelmed by the shock and fear of the diagnosis to have the emotional capacity to talk with other patients or carers at that point. Not at the initial diagnosis because you need to get to grips with tha The term 'peer support' did not always have meaning for participants unfamiliarity led several patients and carers to dismiss 'peer support' as not for them and deterred others. The term could also promote a sense of exclusion or stigma. Some respondents misinterpreted the term. Furthermore, 'peer support' was judged a somewhat cold and unfriendly term by those for whom it was unfamiliar. Respondents thought it sounded professional and inflexible, Acknowledging a need for support was difficult for many patients and carers in this study. self-esteem. Respondents expressed concern about being perceived as overly 'needy' or lacking social resources Projected to me is you are a needy person and I don't like that picture of myself. (Carer 7) Some predialysis participants worried that if they took up formal peer support, it might give clinicians the impression they did not have the ability to manage their chosen therapy. T They did not want to undermine their desired projected image of being sufficiently independent and capable of managing the treatment themselves. Even if they weren't judging you, I think you'd feel they were, well I would. They've trained me, they think I'm ready. (Carer 2) an interest in peer support to clinicians, in case this might be interpreted unintentionally and negatively as a criticism of clinician-based support

	<p>receiving formal peer support intrinsically as a social event, some respondents worried about not knowing the norms, obligations or boundaries.</p> <p>Concerns were expressed about being too shy, unconfident, not very sociable, unable to convey needs and preferring to listen rather than talk. I'm not very sociable. I find it hard to talk to people I don't know so I'd find it difficult to be honest. (Patient 3)</p> <p>Several interviewees felt an unequal exchange might generate an uneasy 'support debt' that would eliminate the potential for ease and comfort in the transaction. I wouldn't feel right if they were just, somebody was just giving me hundred percent and I wasn't giving them something back...If I thought it was one-sided I wouldn't even do it. (Carer 2)</p> <p>formal peer support exchanges would inevitably have some imbalances and be different to most social interactions;</p> <p>If rapport is lacking, it was widely assumed the relationship would not work</p> <p>They anticipated telephone contact being somewhat cold and impersonal and felt it would be difficult to build rapport with an unseen person.</p>
EM17 DiGiacomo, M. et al. - 2015	<p>The refugee health program linked women to a general practitioner, English classes, opportunities to increase health literacy, and information on reproductive health which was important to these women. Unfortunately, not all resources were in their language.</p>
EN01 Ekundayo, Olugbemiga T. et al. - 2012	<p>Lots of people might not have the DVD's</p>
EN07 Hout, Marie Claire Van et al. - 2012	<p>need to raise their profile, and ensure that all users' needs are met.</p> <p>someone needs to take control. The Task Force needs to stipulate goal</p> <p>There is no presence or sense of identity. You have to go looking for it</p> <p>It's more complex than you think. Scope and parameters are needed ... like 'you cant be all things to all people'...small steps are needed.</p> <p>his kind of integration could create difficulties for those in recovery, by reintroducing individuals to alcohol and drug using peer network</p> <p>involvement in other people's lives is detrimental to their own recovery at that stage</p> <p>the majority of providers voiced similar concerns around clients' anonymity and privacy</p> <p>AA is awful. We need something different. It's important to be there to catch those who fail [and] first experiences are so hard</p> <p>Limited time</p> <p>transport</p> <p>Rural clients see the service as city-based and not for them.</p> <p>'if the mountain won't come to Mohammed' spread it across rural areas.</p>
EN08 Carlisle, Karen et al. - 2017	<p>some voices were louder than others</p> <p>"limited" community participation. T</p>
EN09 Flournoy, Minnjuan W. - 2011	<p>funding</p> <p>I think it's been a big help but my concern is what happens when the grant runs out. My concern is what happens if it doesn't sustain itself,</p> <p>too expensive and not covered i</p>
EN10 Brooks, Fiona - 2008	<p>Organisational pressures</p> <p>The patients' council wouldn't necessarily know what needs doing over the next 5, 10 years, but I do.</p>
EN18 Mitchell-Brown, Fay et al. - 2017	<p>social or cultural barriers.</p> <p>affordability</p> <div data-bbox="466 1796 692 1960" data-label="Image"> <p>PERCEIVED BARRIERS</p> <ul style="list-style-type: none"> • Language • Self-Management • Stress </div> <p>I would love to learn about it. They tell me that they will schedule an appointment, but it never happen</p>

	I ask about education, they told me that at the location where they teach about it does not have Hmong translation. So, it's got to be that I must know English, but I don't know English, so I need to find someone that will help me translate, but I can't find one.
EN19 Garcia, Jonathan et al. - 2015	, to avoid what key informants identified as "being seen as a number" or "just a person at-risk" for HIV. , "a lot of service providers don't like EBIs" (effective behavioral interventions) because they were "shortsighted" and "undervalued the staff's work with outreach and community engagement, but that's what's funded." S funding
EN25 Robinson, Nicola et al. - 2015	Overcoming the barrier of stigma
EN35 Gien, Lan et al. - 2017	they're giving each other wrong information, it might be right, it might be wrong..." participants did not mention contacting the diabetic education centers available in the more populous areas throughout the province. They also provide free sessions about DM self- management. It is not known whether participants were aware of their existence or could not use their services due to other reasons such as geographical distance transportation problems, teaching materials that were irrelevant to their local context, and unappealing teaching method
EN39 Durme, Thérèse Van et al. - 2014	patient education is mostly (single)-disease centered.

ANNEX 3: Adherence, self-management and decision-making - Codes and quotations

Table 16 - Facilitators in compliance and adherence

CO06 Graves, K. et al. - 2011	<p>Providers referenced patient motivators for counseling and testing, including concern for family, ability to make more informed medical decisions about risk management, and, for women affected with cancer, helping them more effectively manage their current diagnoses and treatment</p> <p>I think women are motivated by the fact that there is some degree of clarity on whether or not they should have risk reducing surgery or more intensive screenings, MRI, [or] breast exams.—</p>
CO09 Laws, M. Barton et al. - 2012	<p>Some were adherent in spite of difficulties, because they believed it was necessary to preserve life and health</p> <p>like to take my meds on a regular basis.</p> <p>enjoy taking my medication. I have fun when I take it</p> <p>we have to want to do it. We have to want whatever it is that we're going to do</p> <p>accountable for taking your medicine, taking it on time.</p>
CO15 Hart, Ruth I. et al. - 2017	<p>Challenges to initiating and maintaining the recommended behaviours were diverse, relating to: other symptoms and/or conditions; personal responsibilities and resources; individual psychology; and the clarity and immediacy of the "return" on the changes.</p> <p>acknowledgement that their current approach to managing fatigue was sub-optimal</p> <p>significant feature was commitment to follow-up,</p>
CO19 Brez, Sharon et al. - 2009	<p>attitude about "seriousness of diabetes</p> <p>Level of patient "trust" in primary care provider</p> <p>Patient readiness for discharge was consistently associated with patient behaviours and attitudes</p> <p>ongoing ability of patients to adopt and maintain self-management behaviours such as following a recommended diet</p> <p>attendance at specialist clinics helped patients "own their disease"</p> <p>"better compliance" was seen as a hallmark of readiness for discharge from specialist care</p>
CO20 MacDonald, Kath et al. - 2015	<p>trust</p>
CO22 Smith, Sian K. et al. - 2008	<p>giving people a chance to make an informed judgment.</p> <p>explanation of medical terms as a means to inform and empower patients.</p>
CO23 Davies, Jane et al. - 2014	<p>fear as a motivating factor</p>
ED16 Wright, Nicola - 2013	<p>acceptance of their long-term condition, both by themselves and other people</p>
ED9 Santos-Livengood, Christie A. - 2015	<p>Women identified that their sexual health is connected to their gender identity and that maintaining their sexual health is a way in which they protect themselves and their partners from harm. A participant shared: "Obviously being a woman, there's things that I have to get checked on a regular basis. I have to go to a gyno and all that kind of stuff."</p>
EM06 Phillips, Janice et al. - 2011	<p>I guess because I'm getting older now the majority of women in my family developed breast cancer around middle age or whatever, like early 50's and 40's like that- my grandmother and my great grandmother. It's just, I feel that I should be more concerned about it now, e</p> <p>Knowing that my sister has the gene. This is something that I need to be more serious about, that's another reason why I came on in [to be tested]. I have a three- year old daughter that I want to see grow up and graduate from college and high school. I want to be able to see her kids and my grandkids, you know</p>

EM07 Bhattacharya, Gauri - 2012	<p>We particularly wished to listen and learn from the 6 men and 3 women who did not find the dietary changes challenging after they were first diagnosed with T2D. Their responses, if any, were very general: “got to do what I got to do”, “nothing special for me”, or “I can do it all if I need to.”</p> <p>their doctors advised that T2D needs consistent maintenance and self care, including regular monitoring of blood sugar (“pricking fingers”)</p>
EM08 NANTON, V. et al. - 2011	<p>Wives had, in most instances, played an important role in encouraging or insisting on their attendance.</p> <p>help and care they received from their families and considered themselves well cared for and supported</p>
EM11 Nota, Ingrid et al. - 2016	<p>The way of administration is more personal than increasing or decreasing the dosage. Starting to inject yourself is more personal than starting to take tablets.” [Female, 41 years]</p> <p>When starting medication I prefer to share in the decision-making process. Increasing the dosage is something I want to decide myself, as I’m the one who can best determine how severe my pain is. And the doctor decides if the dosage needs to be decreased, because he/she understands what my blood level results mean.</p> <p>Last year I was in so much pain. My knees were killing me. I called the doctor and like a drug addict I begged for an injection. Normally I wait until the next check-up and the blood level results, but now I took control.” [Female, 54 years]</p>
EM12 Wiljer, David et al. - 2013	<p>You take the time...That’s the most important thing. We get rushed through by the doctors. Every appointment, it’s in and out. The nurse, the student doctor, all come in already knowing everything. It’s understandable, they have so many people. It’s nice to be able to sit back and talk with [the clinician].”</p> <p>“I found [the clinician] very easy to talk to...[the clinician] had that sort of personality... was engaging and came across as being interested. That’s important.”</p>
EM17 DiGiacomo, M. et al. - 2015	<p>Professional stakeholder participants discussed that women they worked with, particularly from new arrival and refugee communities preferred face-to-face outreach and female health workers/professionals. S</p>
EN02 Browne, Annette J. et al. - 2012	<p>organizations acknowledge the impact of health and social inequities on health, illness and access to health care</p> <p>Rather than constructing patients as ‘non- compliant’ or as failing to achieve goals, the Centre’s providers recognized how broader contexts influenced people’s health trajectories and decisions</p> <p>patient-initiated appointments scheduled on a drop-in or pre-booked basis</p> <p>Peer-support activities, focus groups</p> <p>Patients often expressed a sense of ownership and responsibility in relation to ‘their’ Centre [I have] a paid position where I’m on call [for janitorial work]. And that helped me, kept me busy.</p> <p>like I’m doing something and I’m being responsible.</p> <p>housing</p> <p>food</p> <p>addressing people’s social needs as fundamental</p>
EN05 Graffigna, Guendalina et al. - 2014	<p>receive specific recipes and examples</p> <p>Illustrations</p> <p>enumerated rules would be of particular use in how to manage the evolution of daily routines</p>

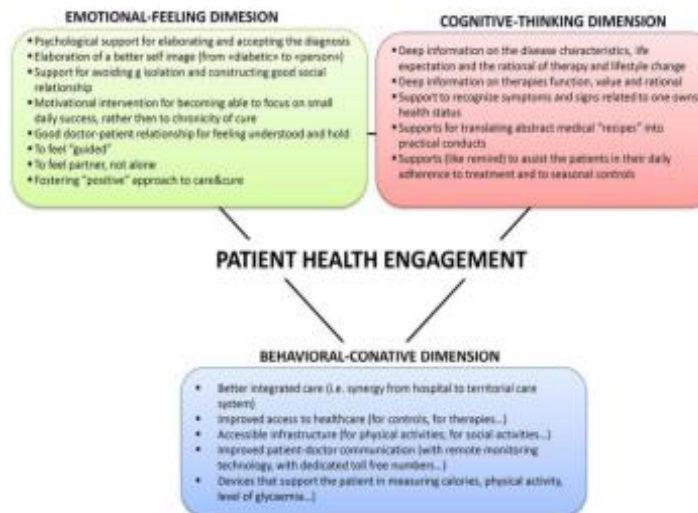


Figure 1 Factors fostering patient health engagement.

o accept this new image of themselves

When I am in control, I achieve better result

motivation is the key. I

the doctor-patient relationship is fundamental in order to develop a positive approach to treatment and to really understand what they need to know how to safeguard their health

someone who could coach me and motivate me in the daily life of my therapy

a mobile tool, or a website that you can use whenever you need, to communicate

EN09

Flournoy,
Minnjuan W. -
2011

Mobile unit

Easy access

No cost for care

Short wait for appointments

Regularity and continuity

Quality of care

Respect/care for patients

Knowledge and skills

Transparency

Communication with

patient

Dissemination of oral

health information

Friendly and efficient staff

Staff training

Communication with patient

Dissemination of program/services information

Reminders

Encouraging statements

no cost for care

the fact that they wanted an appointment and were able to get one in a timely fashion was a reason to return for care

got an appointment much sooner than I thought

clinicians and patients discussed the importance of having open, two-way communication.

friendly demeanor and efficiency of the staff

encouraging statements played a significant role in encouraging patients to return for oral services.

duty to follow given health advice

EN14 Hirjaba, Marina et al. - 2015	My duties are blood sugar monitoring, right insulin dosing and eating and a regular life rhythm you are able to have a better life. Neglecting general healthcare duties caused greater expenses for the healthcare system. Therefore, the well-being of society as a whole was seen as being affected by patient duties. fear of consequences work environment
EN15 Maten-Speksnijder, Ada J. et al. - 2016	Information about the disease is seen as a prerequisite for adherence goal-setting coaching programme
EN18 Mitchell-Brown, Fay et al. - 2017	She is very good and cares for me. diabetes education is important to their care. the group helped me maintain normal blood sugar. They taught me to check my blood sugar and eat good foods.
EN24 Powell, Rhea E. et al. - 2016	their patients' ability to manage their health including: insurance issues; financial barriers; mental health and substance abuse; and housing and transportation need
EN29 Richardson, Lorilei M. et al. - 2016	understanding that a condition was chronic and would require such work for the rest of their lives weighed heavily described remarks made by their primary care providers and topics that their providers brought up to them during clinic visits, thus suggesting to the participant that certain conditions should be priorities
EN34 Natale, Anthony P. - 2009	I think that you need to use scare techniques; before and after pictures. focused on highlighting the systemic negative effects of HIV. identifying specific risks for infection by behavior I am not sure how you would do this, but education on the Internet would help. Not questions that people can read and sift through the information. I think that it needs to be more specific. Like what are the risks for oral sex, and what are the risks for anal sex.
EN35 Gien, Lan et al. - 2017	". Most welcomed having a peer support group, but also stressed having a professional to provide accurate DM information
EN36 CLOCHESY, JOHN M. et al. - 2015	long-term relationship with a provider or a healthcare system.
EN36 CLOCHESY, JOHN M. et al. - 2015	follow-up,
EN37 McCabe, Catherine et al. - 2014	cessation of smoking
EN40 Rise, Marit By et al. - 2013	Health personnel also described that dialogue led to better treatment results: The dialogue and the motivation itself are in the treatment... or a very big part of the treatment. Its not just about getting a pill...
EN45 Young, C. et al. - 2016	Participants also used data to reassure and provide personalised health information to clients. This was thought to promote treatment adherenc

Table 17 - Barriers in compliance and adherence

CO06 Graves, K. et al. - 2011	medical mistrust as a cultural factor in the underutilization of genetic counseling and testing in African American women privacy
CO09 Laws, M. Barton et al. - 2012	In spite of their good current relationships and trust for their providers, not all respondents said they always follow the provider's recommendations do not take their ARVs when they drink alcohol, takes days or weekends off to give his body "a break"

CO10 Burridge, Letitia H. et al. - 2011	. They don't want to "take up the GP's time" is usually the catch-cry and so you just have to sit back and say "I have got plenty of time. H
CO20 MacDonald, Kath et al. - 2015	Clinic is not patient led, patients may not speak there, they'd speak (parental surveillance) minimisation frustration at the amount of self- management they were expected to achieve in accordance with HCPs' expectations
CO23 Davies, Jane et al. - 2014	misunderstanding appeared to contribute significantly to the sense of stigma lack of biomedical knowledge either pushed them to take their tablets to prevent imminent death or made them too afraid to attend the clinic, so acting as a barrier to receiving any care.
CO26 Wray, Ricardo J. et al. - 2009	doctors and lawyers that have prostate issues, but don't seek treatment taboo subject Key informants noted a common lack of routine preventive care among African American men: 'African American men have a history of not going to the doctor' (Key informant).
ED9 Santos- Livengood, Christie A. - 2015	Participants identified differences in safer sex practices based on the gender identities and sexes of their partners. Participants expressed that they were generally consistent about barrier use with their male partners. Many of the participants in our study did not regularly use barriers when they have sex with women, with only one woman explicitly stating that she used female condoms with all of her female partners. But like I've never been with a female partner and offered to use a dental dam or something like that
EM04 Boise, Linda et al. - 2013	connecting people to mental health counseling was often difficult owing to a lack of receptivity of those needing such support I have a part-time job that don't give insurance. I am so afraid of getting sick.* People shared stories of friends who would not go to see a doctor even for very serious conditions because they feared the costs Working through interpreters added to the complication of appointment making, an aspect of health care that was unfamiliar for many. The necessity of using interpreters also deterred some Africans from seeking care because of their fear that private health information might be spread to the community
EM06 Phillips, Janice et al. - 2011	I had a lot of medical bills, and I still do, because it's like, I'm not going to not go and see my doctors just because I don't have any money. I'm not going to die because I can't pay my bills.
EM07 Bhattacharya, Gauri - 2012	dietary guidelines for T2D were difficult and impossible to follow African Americans, they felt distressed that their culturally relevant foods are "not healthy, no good" and immediately experienced a disconnection between their community and the self-management guidelines. Both men and women described several major issues: "no potato," "no fried foods—particularly not chicken," "no sweets," and 'always stay on [the] diet' is my heritage, we eat fast food and fried food" (66 year old woman). A 50 year old woman divulged: "We were taught what to eat, raised on fatty, fried foods, maybe not that healthy." At the same times, as a 55 year old man noted, there was "no money to buy fresh fruit, good food." they share dinner in their churches about two or three times per week. Generally they have potlucks with a "huge" spread of food served according to the buffet system. The participants were worried that attending these big dinners would be mentally stressful The majority of the women participants (75%, 12 of 16 total) were overwhelmed with the thought that they could not possibly engage in physical exercise at least 3 days a week as required after T2D diagnosis. "big" chasm between the guidelines and the practical reality of their lifestyles in their community. Gyms were not available in their area and even if available, would be unaffordable this disconnect between the T2D self- management guidelines and the realities of their lives caused some of the women participants to experience their doctors as "disrespectful."

	<p>'where to walk? The roads are no good. I'll fall and break my hips. Then surgery and a walker!"</p> <p>We walk once in a while to go to friends' houses. No one walks in the countryside</p> <p>They were suspicious of medical recommendations about regularly taking medication. "My doctor told me to take pills regularly. Doctors always say that! I can take care of myself. If I do not feel good, I'll take pills. (53 year old woman).</p> <p>Doctor asked me about my family history—my parents, grandpa, grandma, about all of them. They lived a long life...don't know how many years but did all normal things!! These questions make me feel uncomfortable!"</p>
EM08 NANTON, V. et al. - 2011	<p>Two participants, however, who were to receive hormone treatment from the GP, although ultimately compliant, had initially expressed reservations concerning the treatment prescribed.</p> <p>And I explained to the doctor ...I said, 'I don't want to have this injection' because it's a thing that bloats you up you see and I don't want to do that . . . it gives you breasts and I said 'No' and he's telling me about being like macho man and I said 'No, I do not want to be a macho man, I just want to be me.' (Mr E)</p> <p>, insensitive behaviour by a variety of health professionals with little regard for personal dignity was described by several men,</p> <p>With regard to side effects of treatment, issues of continence were paramount. Men had not felt prepared for the extent and duration of these problems. Little advice had been offered</p> <p>Some men had been told by their doctors that they should not expect to be sexually active at their age. As one man recalled,</p> <p>He said 'You can't do that as when you were a young age man', but me tell him I can accept that but it shouldn't have all gone. (Mr A)</p> <p>family members lived too far away, had little contact or relationships were poor.</p> <p>involved in caring for family members with various ill- nesses or disabilities.</p>
EM11 Nota, Ingrid et al. - 2016	<p>It also depends on how you feel. Actually. If you feel fine, you think:</p> <p>Say whatever you want, but I do not need it, and if you do not feel so good, then I gratefully take the advice." [Female, 41 years]</p>
EM12 Wiljer, David et al. - 2013	<p>several participants experienced substantial stress concerning their inability to return to work or ability to deal with new problems that resulted from their reduced employment and income. This was expressed to the clinician and participants reported the SC helped them find information and advice regarding how to properly manage their current situation.</p>
EM16 Vries, D. H. de et al. - 2016	<p>an effect of nondisclosure due to (the fear of) stigmatizing attitudes seems to be that PLWHA become less adherent to their medication because they, for instance, do not want to take their medicines in front of other people. O</p> <p>"I do not feel good, I am constantly scared to take my medicine when I'm with friends"</p>
EM17 DiGiacomo, M. et al. - 2015	<p>Another professional stakeholder participant discussed that the women she works with may avoid seeking help or may lie to minimize financial shortfalls when unable to refill prescriptions for fear of being labeled and stigmatized.</p> <p>Community participants described their perception that doctors are disbelieving or dismissive of their health complaints, particularly in the case of chronic conditions</p> <p>a source of women's disempowerment was the dominance of men in health professional positions</p> <p>I'm used to trying to get what I want out of the medical system. And I will pursue my goals and get them to fit in with me and do what I want and give me a referral to someone if I want it." (CM)</p> <p>explained as an avoidance strategy: "[Women] will sit there and just go, 'yes', and not take the tablets, because they don't know what it's about. But they tell the doctor they do, because it's easier... and because it's intimidating." (PS)</p> <p>The more chronic the disease, the less...interaction they get.</p> <p>The disproportionate burden of caregiving on women im- pacts negatively on self-care although home visits by nurses were appreciated, socioeconomic disparities would act as barriers if 'Anglo' nurses were doing home visits. Cultural stoicism was also cited as a barrier to home care outreach:</p> <p>"Sometimes it's stoicism around that, from a cultural point of view; where I don't want to show that I'm not looking after my house and making my meals." (PS)</p>

<p>EN01 Ekundayo, Olugbemiga T. et al. - 2012</p>	<p>barriers to care facility usage include unfriendly provider staff attitudes towards the men, fear of discovery, unclear messages (incomprehension), inertia, apathy, unemployment, and lack of insurance coverage for car</p>
<p>EN02 Browne, Annette J. et al. - 2012</p>	<p>marginalization</p>
<p>EN05 Graffigna, Guendalina et al. - 2014</p>	<p>The reliance on drugs is a constant reminder of the patient's illness status lack of adherence to treatment is often a sign of the patient's reluctance to accept the awareness of his/her pathological status. The doctor is ambivalently considered to be the most important point of reference for the patient, and at the same time as far away figure the rationale behind medical requirements. "I try to be compliant with all my doctor said, but I confess that I didn't really understand the sense difficulties in translating these therapies into the structured frame of their daily life scarce understanding of the reasons behind abstract medical prescriptions of therapy and lifestyle change When you travel, it is very difficult to take the drug, it is also embarrassing. Sometimes I forget to take my pills I take a bit more of the drug in order to balance behaviorally disorganized unable to translate information received by their doctor in reproducible and effective behavioral practices incomplete understanding of the reasons the doctor-patient relationship sometimes appears challenging and patients tend to avoid contact "Honestly I hate the controls: my doctor is usually in a hurry, and I don't feel like asking for more details. I feel stupid to ask." "Sometimes I ignore the appointments and I don't go." fail to completely accept their diagnosis, When I go out with my friends for supper, I prefer to ignore my therapy. I feel tired and without motivation</p>
<p>EN06 Walters, Chasity Burrows - 2013</p>	<p>concern about being a burden</p>
<p>EN09 Flournoy, Minnjuan W. - 2011</p>	<p>High provider turnover Limited number of providers Technical challenges Lack of sustainability/funding issues Frequent rescheduling Cost of care Poor attitude Unfriendly/rude behavior Difficulty prioritizing the program turnover clinician was overscheduled or absent Repeated rescheduling because of the small number of providers and their limited availability forced some patients to consider not returning for services often times the equipment would be inoperable. unable to perform certain essential procedures or retrieve electronic dental records Frequent rescheduling of appointments by the clinical staff was highlighted as a barrier to continuous engagement discontent with the altered appointment times. cancel appointments real bad</p>

	<p>"I would get all the way there and find out I had been canceled - AGAIN the medications required to treat some of their oral challenges were too expensive and not covered in the program Patients expressed their discontent for the attitude of a particular provider, and discussed how they had actually decided to not return to scheduled appointments I wouldn't have come back if he talked to me the way that he talked to some of those patients." comments were directed towards the patients by one of the dental clinicians, which caused some patients to discontinue seeking services in the program patient's personality, character and sense of responsibility</p>
EN14 Hirjaba, Marina et al. - 2015	
EN17 Bailey, Kenneth Chase et al. - 2014	the participants expressed a sense of helplessness or "inability to break the chain"
EN18 Mitchell- Brown, Fay et al. - 2017	<p>inadequate follow-up on scheduling diabetes education sessions "No, we have not received any," "I have learned about it but I forgot." Participants expressed a desire to learn about diabetes. "I don't take the medication my doctor prescribed for me much. Maybe just two in one day just to help relieve the symptoms.</p>
EN24 Powell, Rhea E. et al. - 2016	"I had a patient a few days ago who didn't want a home visiting nurse to come out to check his incision because he couldn't afford the co-pay." , mental health and substance abuse issues
EN25 Robinson, Nicola et al. - 2015	the chronic aspect of HIV engages people in their care and provided 'partnership' in treatment
EN29 Richardson, Lorilei M. et al. - 2016	costs
EN30 Cook, Erica J. et al. - 2014	<p>The cost is a big issue especially if you don't have a landline and if you have to do on a mobile phone if NHS Direct was free to access they would be more likely to use the service It's supposed to make life easier but I spoke to a friend of mine who has used it because she's a mum and she had to press that many options that she found it easier to get the doctors to come out than use NHS Direct</p>
EN35 Gien, Lan et al. - 2017	<p>suggesting foods that are unfamiliar or not part of the day-to-day diet creates anxiety and uncertainty for people with DM, challenges their sense of self-efficacy and their ability to self-manage their condition "I went to a dietitian...I don't think I did anything that she said. I have my regular meals. I never ever cut back or nothing". limited access to health information, shortage of health services in rural areas, the importance of cultural consideration and local context reporte reated differently</p>
EN36 CLOCHESEY, JOHN M. et al. - 2015	<p>If I was laying on the street bleeding to death, I would die before I would go to that hospital and let them touch me. the next appointment is going to be another \$200</p>
EN38 Ross, Fiona et al. - 2014	Assumptions that medication is the be-all and end-all
EN42 Fairbrother,	<p>reticence in initiating contact with healthcare professionals Reticence in seeking medical assistance was also attributed to difficulties in obtaining timely appointments</p>

**Peter et al. -
2013**

Table 18 - concepts on self-management

CO01 Sacks, A. Abt et al. - 2016	If you want to be an active part of the treatment, you obviously need a broader education. Of course you have to trust the doctor but you also have to look around yourself and not only make sure that what they are giving you is the best thing and that it's suitable for you
CO02 Dellasega, Cheryl et al. - 2011	encouraged them to be responsible
CO08 Dowling, Joni E. - 2010	relied on the Internet as their primary resource when seeking information to assist them in making decisions about their care second opinion books networking with other women like themselves
CO15 Hart, Ruth I. et al. - 2017	making more time for sleep, taking more exercise and attending more closely to diet.
CO19 Brez, Sharon et al. - 2009	Patient readiness for discharge • "Self management" abilities, "compliance", attitude about "seriousness of diabetes" • "Ongoing access to education" and resources • Level of patient " trust" in primary care provider, strength of relationship with specialist team • Degree of alignment of "patient self management expectations" and treatment goals
CO27 Dolce, Maria C. - 2011	sharing of power and responsibility with their healthcare provider
CO31 Zulman, Donna M. et al. - 2015	A patient described the routine that she incorporated into her daily life to attempt to address overwhelming self-management needs: It's a struggle. It is! It's a huge struggle. Every week I have to put my meds in pill boxes because if I don't do that, with as many different medicines as I'm taking...To be perfectly honest I couldn't even tell you how many pill bottles it really is. Videoconferencing to enable participation of remote caregiver You have to be your own advocate
CO38 Duineveld, Laura A. M. et al. - 2016	I think that some people are able to manage it well, but most of the time, people with cancer want someone else they assumed not everyone would be capable of taking responsibility of his/her own survivorship care, for example, among the elderly, immigrants or poorly educated people ▶ Patients are not willing to be responsible for own care ▶ Patients are not capable of taking responsibility
ED10 Costello, Joanne F. - 2013	recognition of perfectionism as neither possible nor desirable in self-management nobody manages it perfectly, and you could become obsessive compulsive if you try and manage it perfectly. There are times when we just scientifically, we don't have all the answers.
ED11 Dale, Jeremy et al. - 2008	patients generally found the telephone support to be a useful addition to routine care Peer supporters reported that their confidence to self-manage their own diabetes <i>'I'd started to exercise and it made me realise how important diet was'. (P2)</i> <i>'I had started a walking regime'. (P5)</i>
ED13 Nunes, Julie A. Wright et al. - 2015	their current fund of knowledge related to numbers, often listing their experiences using numbers outside of medical care as the foundation for their numeracy skills. They expressed difficulty using these same skills in the context of medical care Units of measurement as a barrier, i.e., the metric system "I'd rather use the pounds system." (59-year-old woman) "I don't too much identify with the metrics." (49-year-old man) Reference to medication dosages "I want them to teach] about the kilograms . . . how much kilograms you need, how much you're supposed to take" [Later, reference to daily sodium intake . . .] "Yeah, that's all I use (each day) . . . about 1 kg of salt" (39-year-old woman) "Math was one of my hardest subjects, [but] in dialysis, I got to do numbers and to . . . write all my stuff down. So I enjoyed it, it makes a difference." (49-year-old man)

	I think the more you know, the better you can deal with it and the more confidence you will have"
	The metric system was also confusing—in particular, related to medication dosing and dietary nutrient restrictions
ED14 Vega, Gema et al. - 2014	patients' (individual and social) viewpoint and context, which determined the way they experienced the disease and its consequences, how they faced them (more positive patients perceived fewer consequences). naturally, if we are left behind for so long in the follow up, well, we tend, without noticing it, to go back down the same path
	Hmm, follow up. Well, I don't, I don't have it. I mean, but I don't look after myself much. Bah! You know, that's what I'm like, you know? I don't know, I am, I'm like that. No, I don't, I don't listen to, and say, "Bah! No worries," and so on.
ED15 Goebbels, Adrienne F. G. et al. - 2012	counselling encouraged them to change their lifestyle behaviours. T
	"Otherwise it just goes by, because it doesn't bother you, you are feeling well(. . .) you have to wait until you have health complaints and then you are actually too late,
	When I go exercising what does this actually mean for what changes for me? What about the blood values, what about the cholesterol? Because I think that this could be the gain, the extra gain.
	"You simply make a choice now, like, I do this and that. Before that, I wanted everything, I wanted everything and I did nothing (. . .). Now it is simply structure, bringing structure into your whole life." (W
	According to several respondents increased physical activity levels contributed to stress reduction and relaxation. They described this as being able to clear their mind and feeling calmer
	When you have stress, things, I also notice it when I had a busy day at work. Then I enjoy these 25 min on the bike. Because I know when I come home it starts with 'mum,mum,mum' and then the other 'mum,mum, mum'. Listening stereo and answering in stereo. Well, then it is pleasant that your mind is clear."
	Relaxation was also identified as a non-health outcome theme in relation to smoking cessation
	"Then [when you don't smoke] you simply continue. And this is a moment, a fag really is a little moment for yourself."
	improved endurance was commonly reported as a positive consequence of increased physical activity
	regular physical activity made them feel stronger, fitter and more energetic. S
	the improvement in endurance also as the experience that physical activity became gradually easier
	"I feel simply less tired, now. Yes, because of the fitness [training
	being physically active, because it provided them with an opportunity for social interaction
	"When you go exercising, you also go there partly for fun. I mean you get some enjoyment out of it
	The benefit of social interaction was also mentioned with respect to smoking cessation. Despite the overall benefit derived from cessation, two respondents noted that they had fewer or less pleasant interactions with other people since they stopped smoking.
	not having a constant urge for a cigarette anymore, which enabled them to focus better on work or other activities.
	Another benefit of smoking cessation experienced by respondents was that they felt fresher and cleaner
	she liked the idea that her lungs will get completely clean again.
	"I hope that I loose another thirteen kilos, but I find it difficult. Yes, because you really have to abstain from things."
	first to overcome withdrawal symptoms and subsequently to handle the risk of relapse.
	"It's so easy for me to start [smoking] again (. . .). I never have it that I think, yuck the first cigarette
	"I also think now I should not become any bigger, because I would like to see my children grow old, and I simply know, heart failure is in our family.
	It all goes a bit slower (. . .) a bit more difficult, you know.

	<p>"Then you know your blood pressure is good, your blood sugar is good, you name it. If it is good, then it is a confirmation that it goes fine (. . .) than you know in any case how you perform physically. Personally, that calms me down.</p> <p>"My partner went to this gym together with me and also at work my colleagues see that I am pretty active and that stimulates them, too</p> <p>we do the groceries. Then I simply don't buy it [unhealthy snacks]. Things that are not in the house are not going to be eaten." (</p>
ED16 Wright, Nicola - 2013	<p>the isolation they experienced as a result of their long-term condition and how this in itself had a negative impact on their health. Self-management programmes facilitated the development of new social networks within a supportive environment and for many the best outcomes related to the companionship and friendships developed through attending the course</p> <p>need to be valued by others</p> <p>have their experiences validated through sharing and helping other people on self-management courses.</p> <p>Attendance at self-management courses led to a feeling of empowerment for individuals both over the long-term condition itself and others' reactions to it</p> <p>It just depends where people are and how willing they are to accept we have to get into a position where people are managing their condition. No one else can manage it for them, you can get all the medicine in the world the whole lot, but a long-term condition is not going to improve. Well the pain can be managed through drugs and stuff but the psychological changes; you are the only person who can manage that.</p> <p>his did not necessarily mean that healthcare professionals became redundant but that their role and influence diminished as individuals moved towards becoming a self-manager</p>
ED2 Barlow, J. H. et al. - 2009	<p>The self-management course is the fact that, basically you're coming back to setting yourself a goal to do and get on with it.'</p> <p>"The action planning [on the EPP] made me get up and do some exercise.</p>
ED5 Albarran, Cynthia R. et al. - 2014	<p>armed with the pedometer and the knowledge of how to use it, they gained motivation to spend time walkin</p> <p>women gained a sense of accountability knowing that promotoras would be checking their log.</p> <p>others pushed past limit-setting and challenged themselves to take as many steps as they could in a given day.</p> <p>Such discoveries made the class content very 'real' and motivated them to implement lifestyle changes.</p> <p>If you aren't well emotionally, you can't be well physically, so then it must be...there has to be a balance and that's why, that's what this promotora did...she helped many people and the...she gave them options.</p> <p>They cited the warning signs and risk factors for heart disease and described with emotion how the video had impacted them. I</p> <p>Through the brochures and charts, they became more familiar with their bodies and learnt how to curb unhealthy eating habits and foster newer, healthier habits.</p> <p>in the past, 'the diets scare you because you are only allowed to eat one thing' and that may not include 'the thing I like the most.'</p> <p>promotoras taught her that 'you continue eating everything, but smaller [portions].</p> <p>it allowed her to eat within limits, which made it seem doable in her everyday life</p>
ED6 Burda, Marika H. F. et al. - 2012	<p>Self-management of one's blood glucose level</p> <p>to acquire and use self-measuring of blood glucose (SMBG) equipment.</p> <p>reliable measurements can be ensured by taking one's glucose meter in for annual calibration</p> <p>It is important to check the instruction leaflet of the SMBG equip- men</p> <p>Knowledge of one's physical response pattern can be obtained by constructing day curve</p> <p>Doctors or specialist diabetes nurses can help to construct and interpret such day curves, be aware that hypoglycemia can occur as a side effect of medication (e.g. insulin and sulfonylurea derivatives). It is important to read the patient instruction leaflets that come with the medication very thoroughly,</p> <p>Since such instructions are not always easy to understand, it is wise to ask for verbal explanation from a doctor, specialist diabetes nurse, and/or pharmacist.</p>

	<p>Quote 1: "The use of a blood sugar meter is really essential! Measuring your blood glucose is important and you have to know what you are measuring. If you don't know ... you'd better ask your care providers or the Diabetes Association DVN."</p> <p>I always want to know the value of my blood sugar that corresponds with a hypoglycemia episode. It is very useful to draw a day curve.</p> <p>In stressed situations, my blood sugar sometimes rises and sometimes falls; it does fluctuate quite a lot.</p> <p>"I inform them because when I have to stop the car to measure my blood glucose, no one is surprised or asks annoying questions</p>
ED7 Hurt, Tera R. et al. - 2015	<p>, "It's like you've got to cut out about 90% of our diet and what we eat." B</p> <p>"It's expected at some point. Black men will be diabetic." M</p> <p>portion sizes, healthy eating without compromising taste and flavor)</p> <p>exercise alternatives.</p> <p>They do not know. Young Black men need to know. They need to go to doctor regularly and get physicals. Most important, they need to listen to what their bodies are telling them."</p> <p>if only the individual changes, the change really might not be sustained</p> <p>My family is supportive. My wife does not purchase items I cannot have.</p> <p>My wife often says to me, "I'm too young and too fine to be by myself.</p>
EN9 Santos-Livengood, Christie A. - 2015	<p>participants reported valuing taking responsibility for their own health and described how this value influences their sexual decision making and behaviors.</p> <p>Participants identified trust as important in their sexual decision-making processes and behaviors. Women identified that when trust is established between them and their female partners</p>
EN03 Locock, Louise et al. - 2011	<p>Empowerment and involvement in managing one's health</p>
EN05 Graffigna, Guendalina et al. - 2014	<p>understanding the rationale</p> <p>less elaborate understanding</p> <p>Even in the case of a "cognitive adhesion" to diet prescription, the patients often report difficulty in translating treatment into the concrete frame of their daily life.</p> <p>understanding of therapy rationale and values lead patient to unjustified "discounts" in drug assumption as well as to occasional "reparative" changes (i.e. increase) in the drug dosage.</p> <p>ignoring controls or by avoiding direct contact with the specialist</p> <p>Food is strongly emotional and at the representational and symbolic level</p> <p>physical activity is insufficiently gratifying for the patient</p> <p>fostering a good self-image, one that is not reduced to the sole identity of being a patient</p> <p>health literacy and the expectation of receiving more detailed information</p> <p>I get doubts that I don't know how to solve</p> <p>networking</p> <p>meetings with patients that share the same clinical experience</p>
EN06 Walters, Chasity Burrows - 2013	<p>Participants' expressed their responsibility to engage in behaviors that protect their safety, and often times their informal caregivers (e.g., friends and family</p> <p>The participants' expression of the notion of shared responsibility does not imply an equal sharing.</p>
EN14 Hirjaba, Marina et al. - 2015	<p>correct and clear information in comprehensible language, with advice, and counselling tailored to individual needs.</p>
EN16 Holmberg, Christine et al. - 2015	<p>I'm taking a step. (...) by taking the pills and following it along I feel like, I'm more in control than if I were just standing back waiting and living in fear o</p>
EN23 Davies,	<p>it depends on having a positive feeling about the patient knowing what to use and how to use properly."</p>

<p>Freya et al. - 2014</p>	<p>, it's not that everyone feels like taking actions independently. Many will prefer talking to their doctors or rather their lung doctors or to be hospitalized</p> <p>ust feel safer only based on having it at home and they feel they have a bit more control</p> <p>there are people for whom it's very important to have the feeling, that they can do something by themselves</p> <p>the use of rescue packs was unacceptable in general and that patients should always have a consultation with a clinician before any prescription medication is used.</p> <p>did not feel comfortable with the idea of patients treating themselves without any assessment or monitoring by their clinician.</p> <p>Some clinicians thought that the strategy was acceptable, but should only be initiated in a secondary care setting</p> <p>only patients who could understand the correct use of self-treatment should be offered rescue pack</p> <p>concerns that the required level of understanding would not be found in all COPD patients.</p> <p>in order to assess their capability to self-manage doctors considered factors including age, literacy, intelligence and learning disability. T</p> <p>some patients seemed to prefer seeing a doctor when their symptoms deteriorated and would not be happy starting medication themselves</p> <p>t patients should be allowed the opportunity to self-manage their condition and that patients were being done an injustice if they were not given this opportunity to feel more in control of their own disease</p> <p>reducing unnecessary delay in the initiation of treatment for exacerbations a</p> <p>patients who might be reticent to contact the doctor when they first developed symptoms and might wait too long for treatment</p> <p>struggle to access prompt treatment for logistical reasons</p> <p>specific side effects from the medication in the rescue packs including osteoporosis, diabetes and diabetic</p> <p>control, antibiotic resistance, allergic reactions and the effect on fungal flora</p> <p>patients may poorly comply with the planned courses – taking incomplete courses</p> <p>some patients would under-estimate their symptoms and delay treatment for too long.</p> <p>patients might be tempted to take longer than appropriate courses due to the positive effect on their symptoms</p>
<p>EN24 Powell, Rhea E. et al. - 2016</p>	<p>many patients were unable to fol- low through with post-discharge plans or engage with regular outpatient services. Multiple participants felt un- able to effectively motivate patients to pursue follow-up after hospital discharge in the setting of substance abuse or mental health struggles</p> <p>rusting relationships with their providers,</p> <p>But because of fear you don't ask something</p>
<p>EN29 Richardson, Lorilei M. et al. - 2016</p> <p>16</p>	<p>condition prioritization were related to the perceived role that different conditions play within one's body and their perceived effect on overall body function</p> <p>the diabetes is the key to all my health problems ... You treat the major disease and you treat the rest of it by treating the diabetes."</p> <p>"I put heart disease first because if that goes it doesn't make any difference. You're not going to be around to worry about the others"</p> <p>with five conditions said, "It's because what I've learned what the kidneys do for your body diabetes, his top ranked condition, affects multiple organs saying, "Because of the aggressive nature of the disease and what it affects; heart, eyes, kidneys, it goes on and on"</p>

Table 3. Reasons for prioritization with operational definitions.

Reasons for prioritization	Operational definition
Over-arching themes	
• Subthemes	
Perceived role of condition in the body: implications/understanding the role for the condition affecting overall body function	
• Conditions linked	Recognition that a condition is "linked" to other conditions, symptoms, and processes in the body, including how treating a condition could possibly impact other conditions
• Untreated causes severe symptoms	Symptoms or secondary issues associated with a condition, particularly if left unmanaged
• Managing condition preserves function of major organs	Recognition that management of the condition contributes to overall health
• Symptoms present daily and condition is chronic	Descriptions of the daily presence of symptoms and/or the chronic nature of a condition
• Family history	Recognition that certain health conditions could be hereditary
• Uncertainty	Not knowing the cause of or how a condition might persist
• Influences on mobility	Condition impedes physical functioning
Self-management tasks: efforts taken by the patient to manage a condition and how it contributes to prioritization	
• Interrupts daily life or challenging to manage	Tasks required to manage a condition are "challenging" or a condition requires a lot of maintenance/time
• Being successful in one's self-management	Tasks required to manage a condition are "easy" or a condition does not require a lot of maintenance/time
• Recency of diagnosis	New management tasks to learn and incorporate
• Cost	Significant or recurring cost
Pain: describing pain as a primary diagnosis and/or a secondary symptom of another diagnosis	
• Chronic pain	Ongoing issues dealing with chronic pain (as a primary diagnosis)
• Pain as a secondary symptom of other conditions	Descriptions of pain as a secondary symptom of other conditions
Healthcare provider condition prioritization; patient perceptions of provider condition prioritization	
• Patient perceptions of provider condition prioritization	Patient perceptions of provider condition prioritization and its relationship with their own condition prioritization

The concept of "control" in self-management e

Being successful in one's self-management efforts

the act of dedicating effort to the management of a condition and seeing positive results from that effort had a strong influence

the relative recency of a diagnosis and the corresponding implications for incorporating new self-management tasks into daily routines

Pain

EN33 McDonald, Ruth et al. - 2008

Something about wanting to be nurtured a bit ... so there's elements of that [expert patient] that worry me. You know, maybe that's something to do with me not giving total control away (laughs) yea

nurses' reluctance to trust patients to self-manage may help undermine the inculcation of self-surveillance in patients.

Nurses depicted patients as often lacking the knowledge and understanding to enable them to manage their condition.

Some people, it's kind of like they want you to do everything for them

ability to make judgments early on about the extent to which patients would be "good" or "bad" self-managers

as time goes on and the patient becomes more informed but then some people don't progress from that,

I don't think they're in a position, when they're newly diagnosed, to consider actually self managing something till they've got the knowledge behind it. So it's probably, you know, a, maybe a year, a coupla years down the li

. it's, there's a lot of that because a lot of them are elderly patients and they don't take it in, you know

Coercion of patients against their will is likely to create discomfort on the part of the nurses since it clashes with respect for patient autonomy (albeit coercion may well be in the eye of the beholder. This explains why nurses claim to respect the patient's right to choose non-compliance, but at the same time attempt to shock and bully them into submission

EN35 Gien, Lan et al. - 2017

complexity of decision making around food i

food decisions, something that they have never had to think about before, were suddenly very complex and unnatural

confusion regarding the desirable level of blood glucose

pricking the fingers was a challenge for some.

, periodic changes in information about DM, its treatment and self-care create additional confusion and uncertainty a

EN37 McCabe,

Confidence in self-management (%) Yes (72%); no (29%)

necessary to holistically self-manage in a primary care context

Catherine et al. - 2014	<p>Functional management practices amongst participants in this study focused on the dispensation, conservation, and regulation of energy levels</p> <p>perform activities of daily living and social activities such as going to the local shop or cooking a meal.</p> <p>Tiredness and weakness a</p> <p>It affects your social end of it, because you just do not have the energy, y</p> <p>patient motivation, coping ability/response, optimism or positivity, overcoming guilt, and confidence in self-management</p> <p>Motivation was particularly difficult with regard to developing an exercise routine.</p> <p>Also very important and others have said it too, is to motivate yourself to do things. a sense of purpose</p> <p>Learning to accept and live with the condition</p> <p>overcoming guilt.</p> <p>Confidence appeared linked to perceived independence</p> <p>Personal hobbies play an important role in maintaining confidence and independence a</p> <p>Compensating for activities no longer possible i</p> <p>The loss of employment was devastating for younger participants in this study and contributed to decreased confidence in self-managing</p> <p>I keep active. It can be tough at times but it has to be done. And the more you push yourself the better you feel anyway ..</p> <p>Support</p> <p>health professional support, peer support, friends and family, and community/social support</p> <p>Technologies used by participants as part of their current self-management practices included the Internet (most commonly referenced)</p>
EN38 Ross, Fiona et al. - 2014	<p>if you mitigate the risk as much as you can patients deserve a chance</p> <p>Clear and timely information giving and explanation 'If I know what is going on I feel more positive and in control'</p> <p>involved in my care</p> <p>in control of myself and my future</p> <p>I would say that we are encouraged to take risks with clients in the interests of their, you know, being able to learn from experiences and not being too curtailing of their personal freedoms. But if anything goes wrong (...) watch the flashy lawyers and barristers and the inquiry and all the rest of it.</p> <p>I think when people can manage their condition better, I think generally it lends itself to them feeling much better bout themselves, they have better self-esteem, are hopefully less depressed, less anxious, more controlled, more empowered.</p> <p>helping people to help themselves by providing information about services available, listening and treating patients as individual people active in their own care, and helping them to feel safe and supported.</p>
EN39 Durme, Thérèse Van et al. - 2014	<p>patient empowerment is central to patient education. This means that patients are better able to express their priorities and preferences</p> <p>associations</p>
EN40 Rise, Marit By et al. - 2013	<p>patient and public involveme</p> <p>There is a crossing point where you no longer take responsibility for the patient. And if this is a patient who isnt capable to takecareofhimself,butchooses...</p>
EN42 Fairbrother, Peter et al. - 2013	<p>many found it helpful to know their oxygen saturation and to learn their 'normal' range by identifying telemonitoring data trends</p> <p>A number of patients used oxygen saturation measurements to inform decisions about their capacity to undertake domestic activities, such as household chores or taking family excursions</p> <p>telemonitoring data to validate their decision to self-medicate and/or to contact healthcare professionals</p> <p>limited engagement in self-management to a lack of acceptance of COPD as a chronic diseas</p>

don't think most of them look at it [telemonitoring equipment] and think, 'Yes, this is my box and I'm going to manage myself with it.'

However, after reflecting on interactions with patients in the intervention group during the trial, professionals described high levels of adherence to telemonitoring. Many considered that patients' access to data combined with increased accessibility of telemonitoring services increased both the depth and frequency of communication between them and patients

the function of self-management was primarily to support patient adherence to medical advice and treatment

Self-management would mean that they were able to see their warning signs independently. . . They would be able to act upon those warning signs appropriately and seek help,

Table 19 - Facilitators of self-management

CO06 Graves, K. et al. - 2011	testing positive for a BRCA1/2 mutation could lead to better access and compensation for follow-up care t family plays in the lives of African American women" "sisterhood
CO08 Dowling, Joni E. - 2010	stayed connected to their support system by receiving cards, letters, or phone calls discuss preventive measures to reduce the risk of developing lymphedema. Social ties and relationships are emotionally important aspects of life
CO13 Venetis, Maria K. et al. - 2018	patient education, and patient marital status
CO15 Hart, Ruth I. et al. - 2017	Understanding fatigue incorporate into your life to make you feel better think about it and maybe analyse it, analyse what you're doing their approach to managing fatigue, and reported making, or planning to make, small but potentially significant adjustments to their behaviour o schedule pleasurable as well as utilitarian activities: changes were efforts to improve general wellbeing making more time for sleep, taking more exercise and attending more closely to diet.
CO19 Brez, Sharon et al. - 2009	compliance "Ongoing access to education" and resources A diabetes passport, maintained and carried by the patient to record the treatment plan and track progress it could help the patient feel kind of active in his own care
CO26 Wray, Ricardo J. et al. - 2009	Participants mentioned a few prostate cancer awareness and screening provision activities underway from service providers, churches, and community organizations, but these activities were typically sporadic and discrete to specific community organizations Leading health care organizations need to engage in trust-building efforts with community organizations and leadership, including hiring more minority clinicians enhance services to minority populations by increasing their outreach, suggested specific efforts to target individual behavior including raising awareness about prostate cancer and screening, the need to encourage declarations from community leaders and others endorsing prostate cancer care-seeking
CO27 Dolce, Maria C. - 2011	required practical information to help them manage their illness at home
CO29 Reimann, Swantje et al. - 2010	parking location Getting your test results back in a timely manner good office organization
CO31 Zulman, Donna M. et al. - 2015	fully aware of their constellation of symptoms and self-management needs

CO32 Greenhalgh, Trisha et al. - 2010	Monitoring and managing long term conditions competed with these other problems for emotional and material resources and was rarely top of the priority list
CO35 Goddu, Anna P. et al. - 2015	self- management barriers and solutions were shared. They also perceived that social proliferation increased their relevant knowledge and taught them skills to undertake behavior change. The foods you eat, vegetables, chicken. That is our culture. The food."
CO36 Wilkinson, Emma et al. - 2014	accept it, once you've got diabetes there are certain things that will sort of happen but those things can be prevented
CO37 Taylor, Elizabeth et al. - 2014	Family as interpreters Family involvement in rehabilitation Cultural influences on rehabilitation
ED11 Dale, Jeremy et al. - 2008	- <i>'It made me aware of my condition in that it made me aware of the needs of where my diabetes was getting out of control, and I think it focused my mind on those areas'</i>
ED11 Dale, Jeremy et al. - 2008	Have you implemented any lifestyle changes as a result of the telephone support? • Changes in diabetes management: - <i>'I'd started to exercise and it made me realise how important diet was'</i> . (P2) - <i>'I had started a walking regime'</i> . (P5)
ED13 Nunes, Julie A. Wright et al. - 2015	"E... provided support for increased patient self-management in dialysis], they told us to write out blood pressures. . . . You had a pad and. . . . we would go to the weight machine and write our weight down, write our blood pressures down . . . I am still continuing to do that. " "I learned from older patients . . . we learned a lot of things from problems they had with numbers . . . on certain things that we didn't know anything about." (43-year-old man)
ED14 Vega, Gema et al. - 2014	Employed patients with economic or family responsibilities experienced their disease much differently than retired patients or homemakers with other kinds of responsibilities. higher levels might have different tools and strategies available to them to face their disease and its consequences: economic level affected the way patients experienced disease, sequelae, and care needs
ED15 Goebbels, Adrienne F. G. et al. - 2012	"Well, I become more aware of it (. . .) what I struggle with, every time. Because I want to change my lifestyle, but I don't manage to he body satisfaction aspect was not equally important to respondents. Some found outer appearance very important, whereas others considered it less important and attached more value to health risk reduction. learned that achievements, such as weightloss or increased endurance are a result of their own efforts to change behaviour.
ED16 Wright, Nicola - 2013	Self-management programmes allowed the experience of a long-term condition to be reframed and participants realised they were important develop acceptance of the illness was a process supported most appropriately through social interaction and the sharing of similar experiences
ED2 Barlow, J. H. et al. - 2009	PP was thought to be more successful at providing the motivation and techniques to translate the advice received into positive behaviour change They felt that the EPP provided more information and support about coping with the psychological consequences 'The self-management course was better because you got to talk to people about their problems. At the cardiac rehab, it was nurses standing in front talking about things reported that they were 'coping better' after the EPP
ED5 Albarran, Cynthia R. et al. - 2014	Many women had been unaware they had a health problem until they enrolled in the programme and realized they had high cholesterol and/or were overweight by 'x' amount of pounds a they received valuable practical help sharing in an open forum,
ED6 Burda, Marika H. F. et al. - 2012	"You have to learn how to prevent and manage hypoglycemia, and in this context I refer to DVN's training courses... You can also learn to sensitize yourself in such a course."

ED8 Sekse, Ragnhild Johanne Tveit et al. - 2014	Through education, guidance and the sharing of experiences, the women gained a clearer understanding of, and vocabulary for, bodily changes. This provided them with answers and insight.
EM04 Boise, Linda et al. - 2013	[Wellness is maintained by] the African diet with its emphasis on fresh, instead of processed foods and cooked at home with healthy oils.* Good health is exercise. People must be physically well to be happy African faith in God* In our Mahber, there are 6 families. Two of us belong to this Mahber, as we were friends in Ethiopia and I came to Portland because of my friend. We contribute money every month so that we have a group saving in Mahber. This money can be used when something bad happens to one of us
EM06 Phillips, Janice et al. - 2011	I just can't do this; I can't do this,' and they would come in, 'Hi Mommy, it's going to be a great day
EM08 NANTON, V. et al. - 2011	Work, family and faith Food, remembered by men as 'fresh' and 'organic', was produced largely by their own families. Food and the Caribbean climate were represented as important elements in maintaining health The two youngest men had less knowledge and little memory of these remedies. Though they also sought dietary ways of augmenting their medical treatment, these consisted of products they had become aware of more recently. . . . they say pumpkin seeds are good for you, so I started to buy some The 11 men with wives, described the women as the centre of the household as their mothers had been in the Caribbean, (she is my queen) and were reliant on them for care From it they drew strength, helping them live with difficulties associated with their cancer, other forms of morbidity and other aspects of their lives such as widowhood or family problems. physically more active, established informal support networks with other local men with prostate cancer church Well, apart from wife my church stands by me with my illness and my friends. Everybody who knew that you were ill will encourage you and that is the help I get. I didn't get it from any (other) organisations. (Mr D)
EM09 Grande, Stuart W. et al. - 2013	Participant 17 indicated that trust and understanding of social behaviors related to right and wrong serve as motivation "somebody is always pushing me to do greater in life . . . so I got these brother[s] to keep me motivated . . . Ultimately, brotherhood appeared to influence the lives of these young men in two ways: (a) it provides a means of support; (b) and it also serves as a daily guide. "it influences my daily life by helping my closest friends around me . . . if they don't have nothing I don't have nothing." "it makes me think about those who didn't have what I have . . . make sure that I can contribute as my other brothers did." Cause if you spend your time with a certain group of people. They're going to impact you more than any other group. I spend most of my time with males . . . so that's why they impact me . . . so it's like eventually they're going to rub off on you. Sometimes in a positive way, sometimes in a negative way,
EM10 Peterson, Jennifer L. et al. - 2012	Of the 81 participants, 73 (91%) had friends or family members who also were infected with HIV, 45 (56%) received services or volunteered in an AIDS service organization (ASO), 24 (30%) attended a support group, and 10 (12%) participated in a one-on-one peer support or buddy program Yes, they [an ASO] have a buddy system and my friend David just left. He moved to Dallas, so I have to find another buddy. But we do everything together, we go out together, we go out to eat, go to the movies, go to each other's houses, work on the Internet, and different things like that. Embedded social networks are those that occur naturally, including spouse/partnerrelationships, and other friends and family members. committed relationship

	<p>For one couple, having HIV and having opportunities for mutual support provided a bond that kept them together, as described in this example: My partner and I—this is the first real relationship that I have been in with another male. I was about to call it quits with him when we found out about the HIV part. For me, that was 7 years ago today. With that coming on, we decided to stay on and at that time we thought we had 2 years to live at the most. There wouldn't be anyone else to put up with us, so we decided to stick it out</p> <p>I: Do you feel that HIV is what kept you together? R: Yes, he's been diagnosed with full-blown AIDS, so we just hang in there and take care of each other. W</p> <p>I don't really ever go to any support groups or anything like that. Talked with a few close friends, some that were HIV positive and some that weren't. And my significant other was diagnosed about the same time, so we at least had that, you know, each other to talk to about it.</p> <p>networks provide opportunities for peer support when others share the disease. information exchange with friends could happen concurrently with casual social interaction; therefore, they were able to integrate social and supportive functions</p> <p>Some of them [social network peers] provide me with a very positive outlook. The support they give me, the hugs, the handshakes, those types of things. When you go through that mental, emotional crisis, I have some peers that come through for me. I can't find the words for it. They come through and pull me out of that rut that I find myself in.... They pull me through and, vice versa, I do the same.</p> <p>With my friends (with HIV), they understand the disease and that I get tired very quickly. When we do activities, they kind of watch for when I'm starting to show fatigue and they either say, "Well let's sit down and rest," or they'll say, "Well, why don't we call it off, the rest of the thing off, and do something else later?"</p> <p>network support by allowing socializing and bonding, instrumental support through monitoring the participant's well-being, and esteem support by providing an atmosphere of acceptance and self-worth.</p> <p>Well one-on-one versus a big group. You can get a lot more individual attention and focus on the one person. That voice can have a lot more control. It is always amazing how people will open up more in a one-on-one. They disclose more</p> <p>The one [friend] I do talk with I've known for a long time, he is HIV-positive, and he knows my ex who gave me this. So he and I talk a lot. I feel more comfortable with him than I would in a support group. N</p>
EM12 Wiljer, David et al. - 2013	<p>Participants were able to reflect on their diagnosis, treatment and strategies for carrying out their goals and were motivated to implement the recommendations given to them by the clinician</p> <p>"...I had a better understanding about who I could turn to for what because it is a little confusing...you do end up having several different doctors, sev</p> <p>I learned about my cancer, about my stage, [the clinician] helped me understand that a little bit better. I wasn't sure whether that changed with the treatment and [the clinician] helped me understand..."</p> <p>"It verified some things...what to expect after some of the treatments, effects on my body, like the exhaustion. I was telling [the clinician] some of the things I was experiencing..."</p> <p>"...I already have a pretty good understanding of my diagnosis. I don't think [the clinician] could have really told me anything that I didn't already know."</p> <p>The scheduling of the SC at the proper time during the trajectory their cancer care was found to be extremely important. Participants acknowledged that the scheduling of the SC is completely dependent on the individual and should be scheduled when the patient is physically and emotionally ready</p> <p>A majority of the participants mentioned if the consult was held at the beginning of their cancer journey, they would have found it much more useful.</p>
EM13 Kowitt, Sarah D. et al. - 2015	<p>verbal discussion of peers' problems and contexts presence or shared activities without discussion of problems, such as praying for/with peers or talking about family.</p>

EM15 Taylor, Francesca et al. - 2016	Participants were also keen to make active comparisons with others in a similar position, to compare positively upwards not downwards
EM16 Vries, D. H. de et al. - 2016	<p>"After I told my colleagues about my HIV they were much more understanding. They are now able to support me by, for example, asking me how I am doing" (R 51).</p> <p>"By being open about my HIV to people in my close environment, I received understanding and support. It also helped me in processing everything" (R 405). M</p> <p>"Through divergent reactions of others about my HIV, I have experienced personal growth. I became a lot stronger through this" (R 128). Disclosing even helped some participants in personally accepting their HIV-positive status</p> <p>"by disclosing my HIV-positive status to others, I came to accept myself" (R 64)</p> <p>"by being open about my HIV more often, I have become stronger and more confident about myself" (R 70).</p>
EM17 DiGiacomo, M. et al. - 2015	<p>One participant spoke of a female specialist who always books an interpreter for patients from non-English speaking backgrounds, regardless of accompaniment of a family member</p> <p>There wasn't always enough [interpreters]. Um, it depends on the language, too; some are hard to get. Maybe Turkish or something like that might be hard to get. But we had their [phone] numbers and we certainly used to ask if they wanted an interpreter, because we didn't like their family accompanying them in to the doctor, because a lot of those women wouldn't want to say various things in front of their children, for example,</p> <p>Professional stakeholder participants discussed that women they worked with, particularly from new arrival and refugee communities preferred face-to-face outreach and female health workers/professionals. S</p> <p>"I mean, those opportunistic outreach opportunity - like the shopping centres, community events or just community thoroughfares, those places where women frequent, I think having a presence, an appropriate presence by the health service...There's some work around mobile services in disadvantaged communities, which have been successful for women." (PS)</p>
EN01 Ekundayo, Olugbemiga T. et al. - 2012	<p>Prevention behavior needed</p> <p>risk awareness</p> <p>early screenings</p> <p>annual screenings</p> <p>culturally competent communications; having a community spokesperson; increase health literacy, working through community identified centers of influence (clergy, etc), centers of living and social activities (barber shops, salons, churches, work places) and transit (billboards, etc) were also identified. It was also suggested that health professionals should be involved in health fairs and that the use of technology including DVDs should be limited as many people might not have the hardware to use DVDs.</p> <p>free screening in emergency rooms</p>
EN02 Browne, Annette J. et al. - 2012	<p>Having a meaningful focus and daily routine</p> <p>involves working with patients to facilitate access to social housing, food, and clothing, or supporting efforts toward paid employment</p>
EN03 Locock, Louise et al. - 2011	more information, which had not been an original motivator but would now make them think positively about taking part another time
EN05 Graffigna, Guendalina et al. - 2014	<p>an adequate motivation at the emotional level in order to make sense to the changes they are doing in their daily life.</p> <p>These patients need to be empowered and helped to feel "successful" again</p>
EN09 Flournoy, Minnjuan W. - 2011	<p>Mobile unit</p> <p>Easy access</p> <p>The van is really nice - it's like a small dental office on wheels and it's right here!"</p>
EN14 Hirjaba, Marina et al. - 2015	Duties towards work and school colleagues referred to their duty to inform them about diabetes
EN14 Hirjaba, Marina et al. - 2015	<p>I have a duty to upkeep myself. If I do not take care of myself, my family at home will suffer if I am not we</p> <p>If something happened to me, they would be able to help.</p>

	travelling reasonable distances to the hospital or poly- clinic, proper ambulance services
EN19 Garcia, Jonathan et al. - 2015	“fight marginalization.”
EN24 Powell, Rhea E. et al. - 2016	Participants suggested that individual providers and health systems should have more visibility within the communities. increased health system outreach to better identify community-specific needs and to establish partnerships between communities and health providers would strengthen community trust.
EN25 Robinson, Nicola et al. - 2015	Improving patient satisfaction reducing inequalities w Cost reduction
EN29 Richardson, Lorilei M. et al. - 2016	the notion of conditions being linked to one another within the body was significant, and they described how they felt that one condition could influence another condition diabetes as his number one priority, one participant with eight conditions said, “Well, because it complicates any of the other issues” influence of symptoms on their mobility, including concerns about how a condition caused physical disabilities and impacted their ability to walk, work, and keep medical appointments, limiting activities, and leaving them dependent on other Participants discussed a condition as a priority in this context when the condition was demanding, interrupted daily life or treatment, or when medical monitoring was required
EN34 Natale, Anthony P. - 2009	Give people a way to calculate all of the risks they are taking so that they are informed.
EN40 Rise, Marit By et al. - 2013	If patient involvement has as wide a definition as I think it has... it would mean... to have a shared responsibility... and sufficient self-knowledge to be able to reach a goal and a result...
EN45 Young, C. et al. - 2016	Data were used to educate clients about lifestyle risk factors (eg, smoking) associated with poor health out- comes, and to encourage healthier lifestyle choices.

Table 20 - ICT, IT, eHealth and mHealth

CO08 Dowling, Joni E. - 2010	the Internet as their primary resource used the Internet to assist her decision making. In her research, she found a test called CYP2D6, which determines how individuals metabolize Tamoxifen. YWWBC2 also used the Internet. She found an article indicating individuals like herself, whose diagnosis was DCIS comedo, needed an additional pathology staining to determine whether parts of the cancer were invasive Most women used Web sites like Web MD (www.webmd.com), American Cancer Society (www.cancer.org), Breast Cancer.org (breastcancer.org), Susan G. Komen (www.komen.org), and Young Survival Coalition (youngsurvival.org), to get information to assist them in making decisions. Y The first thing I did was cruise the Internet It was a great help. I knew what my options were from researching it on the Internet. they advised me not to go on the Internet because of getting overwhelmed with information active member of a BreastCancer.org blog where women talked about their treatment, which helped her to distribute a recommended list of Internet Web sites. wished for a list of recommended Web sites to assist women in the decision- making process I read the Internet and asked peers, then wrote down questions for the next time I saw the oncologist.
CO23 Davies, Jane et al. - 2014	preference for an electronic format interactive pictures and less text.
CO27 Dolce, Maria C. - 2011	lack of clinical expertise in treating their disease and, consequently, turned to the Internet online support group e-mail contact with persons who answered my questions, helped reduce my fear, and helped me come to terms with my diagnosis

	<p>the Internet to diagnose themselves</p> <p>a lack of informational support related to procedures and were better prepared after seeking information on the Internet</p> <p>Another survivor found reading blogs written by other patients who had experienced a procedure to be helpful and wrote, "I could better relate to their experience and it helped to know what to expect from a physical and emotional perspective."</p> <p>found help from their online communities</p> <p>Stories were shared about needing "emotional support" and turning to online communities. grateful for the Internet</p> <p>The Internet allowed me to track down a couple of journal articles relating to this [off-label] use, which helped persuade my doctor</p> <p>Thanks to the Internet, I pushed for what my daughter needed</p> <p>Cancer information verified through online resources influenced survivors' choices and care decisions.</p> <p>I was able to get information about treatment of carcinoid that conflicted with what my oncologist said— so I sought several specialists' opinions and they all agreed, but conflicted with the oncologist</p>
<p>CO31 Zulman, Donna M. et al. - 2015</p>	<p>I can save myself easily 15 or 20 visits a year just by messaging my [providers] tools that could provide information about their multiple conditions, such as websites</p> <p>have it consolidated in one place^ and mobile devices Bpreloaded with apps that help with certain conditions.^ Patients also desired task management applications that crossed health care systems: BIt would be great if I could just get a monthly reminder that I could print out what was happening this month at all my different [clinics].^</p> <p>Online resources that consolidate information about MCCs</p> <p>Bundled apps for MCCs</p> <p>Organizational apps and web-based programs to assist with complicated medication regimens</p> <p>Centralized reminder system that integrates information from different health care systems</p> <p>Apps and web-based programs that communicate self-management practices to provider</p> <p>User-friendly automated reminder systems about daily self-management activities</p> <p>Online support groups</p> <p>Many patients had experience using technology to detect potential medication interactions the telecommunication, would save time, money, effort, miscommunication, a missed appointment, confusion, frustration...</p> <p>technology in these situations to research their health conditions and actively participate in health care decisions</p> <p>technology empowered them in their role as advocate</p> <p>...tried to arm myself with enough information with the technology, with the right care providers so that I control the disease; the disease doesn't control me</p> <p>patients desired resources that consolidate and synthesize information about MCCs, such as applications that help identify potential medication-medication or condition-medication interactions.</p> <p>Patients expressed interest in resources that would provide high-quality mobile app Bbundles^ that address their specific conditions as well as apps that provide assistance with common self-management challenges (e.g., complicated medication regimens) and integrate information from different health care systems (e.g., appointment reminders).</p> <p>patients described a need for online resources that would connect them with patients who had similar MCC profiles and support their roles as experts and advocates.</p> <p>videoconferencing and other tools (e.g., mobile apps) that would facilitate caregiver participation and engagement in their care</p>
<p>CO32 Greenhalgh, Trisha et al. - 2010</p>	<p>Strategic and business cases for HealthSpace did not mention patients' expectations of personal electronic health records, motivation to use them, or current self care practices.</p> <p>The main experts identified in strategy documents were software developers and national implementation leads; neither clinical nor patient expertise was mentioned</p> <p>A lengthy risk assessment focused exclusively on technical and procedural risks (such as "inadequate specification of requirement by NHS," "information governance and data security requirements [may] change," and even that</p>

	<p>uptake of Health- Space accounts would outstrip capacity to process applications⁴⁰). Risks linked to people's feelings, motivation, and values (for example, lack of interest or a perception by patients that the software was not helpful) were not listed.</p> <p>The 21 people in this substudy who tried using HealthSpace found it of limited value. None entered any health data on to it and none intended to continue using it in its present form, although some anticipated that a future upgraded version might be more worthwhile</p> <p>did not see basic HealthSpace as adding value in managing their condition</p> <p>self monitoring of health data involves a complex interaction between patient and clinician and that the process of entering and accessing data cannot be meaningfully separated from the wider care relationship</p> <p>the "sleeping gym membership" phenomenon: registering for HealthSpace, accessing it once, then losing interest.</p> <p>Three of the 20 agreed to try HealthSpace, all of whom abandoned it soon after first accessing it and declared that they were not interested in using it again</p> <p>Some people in this subsample had no access to computers or the internet at home. Most participants saw these technologies as serving other purposes in their lives (games, shopping, social networking).</p> <p>Some were already using or exploring other ways of documenting and monitoring their condition, such as paper (especially the widely used blood glucose diaries supplied free by manufacturers of monitoring devices) or bespoke software (for example, Excel spreadsheet)</p> <p>One participant who had tried HealthSpace, later became interested in downloading a digital personal organiser (iPhone apps) and found these more fit for purpose than HealthSpace.</p> <p>online self help group hosted by a charity for patients</p>
<p>CO33 Vilhauer, Ruvanee P. - 2014</p>	<p>Women who lived in rural areas without easy access to FTFGs, and women who had difficulty attending FTFGs because of illness symptoms or treatment side effects</p> <p>it was great having a support network, you know, in my computer room</p> <p>When I wanted to interact with people and when I didn't, it was totally under my control.</p> <p>it took me so long to read the mail, that by the time it came for me to write, I was too tired to write</p> <p>with online support, there's chances that you could find somebody at 2 and 3 in the morning that you can talk to."</p> <p>messages could be read long after they had been sent.</p> <p>information is still there</p> <p>it's a treasure trove</p> <p>support was constantly available</p> <p>more opportunity for getting their concerns heard</p>
<p>CO38 Duineveld, Laura A. M. et al. - 2016</p>	<p>System to schedule patient visits</p> <p>They requested a system to call patients for scheduled visits, because they feared follow-up appointments would be forgotten by patients and/or themselves.</p> <p>time investment should be assessed in advance, to determine whether it is feasible.</p> <p>patients would gain insight into their own symptoms and concerns</p> <p>the use of eHealth in general as they found it impersonal, and preferred exploration of symptoms and concerns by themselves</p> <p>eHealth would only be suitable for patients who are highly educated and young. The elderly, poorly educated people, people with no computer skills, illiterates and immigrants who are not able to understand</p> <p>the use of Oncokompas2.0 could cause arousal in patients, by showing them a list of problems that could occur.</p> <p>empowered</p> <p>relieve the workload of GPs</p> <p>Increased insight for both GP and patients in case of vague symptoms and problems</p> <p>Impersonal</p> <p>Not suitable for all patients</p> <p>▸ Increases patients' awareness of problems</p>

ED10 Costello, Joanne F. - 2013	So the technology isn't there for this to be managed perfectly
ED11 Dale, Jeremy et al. - 2008	telecare supporters indicated that they all enjoyed helping others and derived personal benefits, such as improved knowledge, attitudes, skills, social relationships, and insight helped them implement lifestyle changes, such as regular exercise, healthier diet and weight loss.
ED9 Santos-Livengood, Christie A. - 2015	receiving their sexual health knowledge from the Internet, friends and health care providers, and trust their doctors above other sources
EM10 Peterson, Jennifer L. et al. - 2012	Support groups that meet online are increasingly being used the online group allowed him to connect to people who he perceived to be similar to him, this participant did wish for the face-to-face contact that some (but not all) members of the group were able to experience.
EM12 Wiljer, David et al. - 2013	the effectiveness of using eCancer as an interface to creating a survivorship care plan (results reported in another manuscript) was helpful for some participants with their feelings of 'being rushed' by providing structure and keeping the clinician and participant more focused on the conversation
EN01 Ekundayo, Olugbemiga T. et al. - 2012	f technology including DVDs should be limited as many people might not have the hardware to use DVDs
EN01 Ekundayo, Olugbemiga T. et al. - 2012	technology divide between this low income community and the rest of America represents a continuous source of disparity in health information access for African Americans
EN04 Cook, Catherine - 2012	When I used the internet I didn't have to worry about anyone seeing me as I have a laptop at home I think online talking is very good as you can speak to people in the same situation who are having the same problem The internet has been my most used resource about HSV. It's available 24 hours a day to answer any questions I have. It I found the herpes website to be most informative as the doctor is too expensive just to go to for a chat ...it has been through my own research on the internet, some good, some bad to decipher the research that is out there and filter out the propaganda and fear-based support groups (V
EN05 Graffigna, Guendalina et al. - 2014	I search the Internet in order get answers." a mobile tool, or a website that you can use whenever you need, to communicate I would like to have a remote control, a kind of telemedicine tool to feel controlled and supported
EN15 Maten-Speksnijder, Ada J. et al. - 2016	the mother says: 'I don't believe Femke really understands what is going on with her and the disease'. Femke reacts: 'I do understand, but I don't believe the half of it.' The NP shows Femke were she can find a lot of information about the disease on the Internet. She explains: 'this could be helpful to explain to others what it means to have rheumatoid arthritis.
EN19 Garcia, Jonathan et al. - 2015	. They felt there was a contradiction that on the one hand the center had reduced its opening hours because of funding cuts, but on the other hand the center was expanding its computer lab NHS Direct users had a good awareness and understanding of the service I've heard about it it's supposed to make life easier

EN30 Cook, Erica J. et al. - 2014	None of the NHS Direct 'users' were concerned that it was not a face-to-face service. In fact, many 'users' highlighted that they preferred the lack of face-to-face contact, and viewed the service as both personable and professional which provided them with the level of reassurance they needed.
EN32 Hogden, Anne et al. - 2012	The Internet is so varied, that, we have patients regularly sending in information going, 'Oh, I've found this amazing machine that's going to solve all my problems'. And having to tell them, 'I realize you've found this and all the things sound really good, like online there's all these wonderful reviews about this system, but it doesn't work.'"
EN34 Natale, Anthony P. - 2009	MSM suggested that education efforts highlight physical, psychological, economic, social, and sexual effects of living with HIV disease. One suggestion involves creating a method, perhaps for the Internet, for MSM to assess how HIV impacts the lifespan, I am not sure how you would do this, but education on the Internet would help. Not questions that people can read and sift through the information. I think that it needs to be more specific. Like what are the risks for oral sex, and what are the risks for anal sex.
EN35 Gien, Lan et al. - 2017	foods mentioned in the internet are not available locally "Some of the things they suggest you eat is things that I haven't heard of", "You'll never find it (in this province)".
EN37 McCabe, Catherine et al. - 2014	distinct lack of online information related specifically to the Irish context I've been on the British Lung Foundation and different sites on the Internet but they do not give a proper breakdown of things. And most of it is American, which is different to us, they have different facilities to use a ICT use (%) Standard mobile phone (91%); smart phone (25%); desktop home computer (25%); laptop (25%) internet connectivity (%) Have access to Internet based resources (50%); have access to an Internet connection (53%); use Internet daily (25%); use Internet a few times a week (9%); use Internet a few times per month (6%) Confidence in ICT use (%) Fully confident (50%); partially confident (16%); neutral (12.5%); not confident (6%); nonrespondents (16%) Another thing about people on the internet you know at least if you look up what other people are going through you think oh I'm not that bad or you know it can make life a bit more bearable because during winter months I'm more or less indoors."
EN39 Durme, Thérèse Van et al. - 2014	The progressive generalization of electronic patient records within settings and the ICT federal platform of social security (eHealth) have allowed for shared information linking clinical files with built-in algorithms should support clinical decision-making. there is currently a lack of aggregated data for quality management purposes. Informants also stressed the lack of built-in algorithms for assessing the incompatibility between drug prescriptions. care providers in the study had heard about the ICT federal platform for the first time during our focus groups. (Social worker, 1st focus group) "It should be made possible for the patient to access his data, in order to claim the care or service provision to which he is entitled: preferential reimbursement rates, etc." Professionals and patients expressed fear regarding the security and privacy of sensitive data reluctance to use shared electronic data files (GP, 3rd focus group, about electronic patient records) "This is very positive, but raises some ethical questions, because the patient might be unwilling to share his/her data. Important safety procedures should be set up."
EN42 Fairbrother, Peter et al. - 2013	increased their knowledge of their condition reinforced their decisions to adjust treatment or seek professional advice through practitioner monitoring, provided a sense of reassurance and support. embraced enthusiastically telemonitoring would safeguard their health and support greater understanding of their COPD. easy to use

	<p>access to clinical data about their condition which they considered beneficial in determining their state of health and recognizing illness. I</p> <p>prevent exacerbations and hospitalization.</p> <p>you can just take a reading and say; 'well, I do need a doctor or I do need to start these steroids.</p> <p>It gives me a lot more independence. I am not dependent on making the judgment myself. You're using measurements which normally wouldn't be available to me as a patient</p> <p>accessibility of the telemonitoring service</p> <p>reassurance</p> <p>watched over' by telemonitoring professionals</p> <p>". . .you still get the same attention [as 'usual care']. In fact, I'd say you get better because if [telemonitoring staff member] comes on the phone and she'll say "I think you're needing to speak to the doctor'</p> <p>He accredits that to our service and the machine, and is petrified that when the trial ends that machine will be taken away from him, because it has become his life line. . . he's become dependent and believes he should be getting phone calls on a regular basis. (Community respiratory physiotherapist, telemonitoring team</p> <p>I feel it reinforces a sick model for the patient. . . the patient would see themselves as very unwell on a daily basis because they're constantly focussing on their disease state. (Nurse, secondary care</p>
EN44 Gagnon, et al - 2014	<p>Even if we look at quality and safety, we do not look at them from the same viewpoint as the patient</p> <p>patients' viewpoints gave them a wider perspective and enabled them to obtain information that was not necessarily available otherwise</p> <p>Consideration of the patient's viewpoint could improve the appropriateness and applicability of recommendations</p> <p>providing more context</p> <p>usefulness</p> <p>patients could contribute to better acceptability, adoption and implementation</p> <p>improve the quality and efficiency of service</p> <p>to remain focused on the main beneficiaries of the decisions</p> <p>underscored the importance of patients being consulted in order to increase their autonomy and empower them</p> <p>the greater the potential impact of a technology on a patient's quality of life, the more relevant it was to involve them in assessing it.</p> <p>the type of technology cannot be considered alone. The specific evaluation questions and the kind of decision to be made are also factors to be considered in estimating the relevance of patient consultation</p> <p>Given that topics are varied, and even for us, it's always difficult, at the beginning of the research, to become knowledgeable about the technology</p> <p>the patient affected by the technology (or a close relative) should be involved in patient consultation.</p> <p>the need to select participants based on specific criteria, notably previous experience and qualities</p> <p>patient representative in the evaluation process must be a 'generalist' who does not represent a particular interest group or domain.</p> <p>several participants (principally in the focus groups) believed that the patient affected by the technology ('specialist') should also participate in the evaluation committee.</p> <p>experience was lacking among respondents. Hospital- based HTA units are still recent and many hospital managers and HTA producers felt unprepared for the integration of the patient's viewpoint:</p> <p>fear of slowing down the assessment process</p> <p>increasing its complexity</p> <p>diverting the focus of the evaluation towards less essential aspects</p> <p>additional time and costs (</p>

	Biases and industry lobbies associated with some patient groups also worried respondents from hospital
	lack of knowledge and tools to help with the integration of the patient's perspective in HTA
	additional workload
	to have targeted evaluation objective
	on clearly defining the objectives of patient involvement
	only involving patients if their contribution would have a real impact
	to avoid creating false expectations.
	Time constraints, complexity and heaviness of the approach
	well-targeted consultation objectives and specific dimensions to be analysed
	Lack of financial and human resources in limited hospital budget
	Complexity
	multicultural contexts
	fear
	loss of control
	Patient representatives particularly emphasized the medical and scientific jargon used by HTA committees
	sufficient number of patient representatives on committee
	careful selection with well-established criteria
	preparation as well as clear information on their role
	Organizing separate meetings with patient representatives and discussing their role before the HTA committee meeting
	to maintain the same
	patient representatives in committees for a couple of years.
EN45 Young, C. et al. - 2016	Data collected from the participant's own ACCHS, or from the local area, was often trusted more than data derived from more distal sources
Table 21 - Barriers in self-management	
CO04 Delea, Sarah et al. - 2015	changing living arrangements, multiple health issues, family matters and the stress of having to manage medical demands around a personal life "if you ask me, after you have your leg off you'd want a lot of help. You'd want someone coming in every day you know? No one came around talking to me."
CO05 Mota, Lorena et al. - 2015	Communication challenges
CO06 Graves, K. et al. - 2011	There may be a disconnect to how information [about genetic counseling and testing] is presented. [Is it done in a] culturally sensitive manner or is it not conveyed adequately to minorities? less involved in their health potential negative impact of test result on family communication "don't want to know"
CO08 Dowling, Joni E. - 2010	the schedule wasn't feasible class was at night
CO10 Burrige, Letitia H. et al. - 2011	it is disappointing to have to wait weeks for an appointment she was unlikely to discuss her own health with her GP as consultations seemed to be "rushed, or you are in and out"
CO12 Rubio-Rico, Lourdes et al. - 2014	Poor language proficiency among Maghrebis
CO15 Hart, Ruth I. et al. - 2017	No one reported having professional support to identify or implement fatigue management strategies
CO19 Brez, Sharon et al. - 2009	Inability to easily access or afford these services maintenance of "expensive poly-pharmacy" initiated by specialists it was not possible to translate certain key words such as 'liver' and 'kidney' accurately into Yorlaju

CO23 Davies, Jane et al. - 2014	<p>adequate explanations of hepatitis B were challenging to achieve even with a translator. An Indigenous community member working as a translator, however, said that this was not true</p> <hr/> <p>low levels of health literacy and poor health outcomes in Indigenous Australians</p> <hr/> <p>language as the single most important feature of any potential educational resource and also as the most significant barrier to achieving effective cross cultural communication</p> <hr/> <p>lack of shared understanding</p> <hr/> <p>a well-respected senior male elder in the community may feel uncomfortable with having a younger female interpreter in a medical consultation, as it would infer something negative about his knowledge of the subject or ability to understand the health care worker and so decline the assistance of an interpreter altogether</p> <hr/> <p>to speak honestly and in detail about hepatitis B was felt to be culturally difficult between individuals of different gender</p>
CO26 Wray, Ricardo J. et al. - 2009	<p>Community gatekeepers need to be more responsive</p>
CO31 Zulman, Donna M. et al. - 2015	<p>patients with MCCs have to manage a high volume of personal health information</p> <hr/> <p>this challenge as a multiplicative one, with the Bpaperwork^ increasing with each health care encounter: You are trying to manage your health and, believe me, every time you see the doctor and you've got different conditions the paperwork just starts mounting</p> <hr/> <p>Different providers sometimes give conflicting advice/recommendation</p>
CO36 Wilkinson, Emma et al. - 2014	<p>oh my God, what am I supposed to eat now?" I was confused. So one of the nurses said: "oh just eat normally except no sugar and less butter and...</p> <hr/> <p>I don't put in the mind to the diabetes, because if you put in your mind you get more worse.</p> <hr/> <p>it's in the mind</p>
CO37 Taylor, Elizabeth et al. - 2014	<p>lack of flexibility delayed the assessment and treatment process, and therapists expressed feeling less efficient.</p> <hr/> <p>individuals holding a belief that they were ill and should wait to get better, rather than engaging in rehabilitation</p> <hr/> <p>he said that we were trying to rehab in a European manner,</p> <hr/> <p>lack of understanding of the prevailing cultural attitude regarding rehabilitation and recovery</p> <hr/> <p>functional tasks were culturally inappropriate for an individual to perform with a therapist present</p>
ED10 Costello, Joanne F. - 2013	<p>in my ... support group actually where one of the women said, 'When I have an asthma attack the only thing that works is to take a big drag off a cigarette.' And so we had to review that. The misinformation—sometimes we can get into a little tug</p>
EM03 Goldenberg, Shira M. et al. - 2016	<p>HIV/STI testing and counseling was noted as particularly needed for recent arrivals from other countries and rural communities, who often had limited (if any) previous exposure to HIV/STI prevention or testing, as most had not engaged in sex work prior to their arrival and came from more conservative communities where access was constrained</p> <hr/> <p>, HIV testing offered through research studies also carried potentially negative consequences due to the social, economic, and legal consequences of a potential positive test result—concerns which were exacerbated for migrants</p> <hr/> <p>Ah, we are foreigners, and if we get the [HIV] tests done and they turn out bad, they're going to send us to hell, because they're going to say that we're infecting people here and we're not even from here.</p> <hr/> <p>Fear of negative consequences of HIV testing w</p>
EM04 Boise, Linda et al. - 2013	<p>We expect when we come to America, everything is going to be easy, very easy to get, the land of resources. But we soon find out we are struggling to make ends meet, just to make enough money to fulfill our basic needs, such as eating, dressing up, and supporting our family here and in Ethiopia. So to go beyond that and worry about our health, and how to navigate the bigger world outside is quite overwhelming and frightening.*</p> <hr/> <p>My brother recently got laid off from his work. He has three children. He is distressed and is going into depression. Because culturally we don't talk about depression issues, this is very difficult for him to get help</p> <hr/> <p>But since we don't like to admit it and we are nervous about discussing this, sometimes it becomes too late by the time you try to seek care.*</p> <hr/> <p>stressfulness of their lives and the impact these stressors had on their health and well-being (</p> <hr/> <p>the little information we get is simply by talking to friends who have been here before us.*</p> <hr/> <p>No, I never go to the dentist. I worry about it but I don't have one I can go to</p> <hr/> <p>What health care? We don't have health care. They give our children and women health care but we have nothing.</p> <hr/> <p>Cannot trust the translation services, they don't work on the phone and sometimes they don't want the services of the available translator</p>
EM06 Phillips,	<p>My mom can't accept if I was sick. She can't accept that, so it's like, "all girl, you go ahead on," this that or the other. "What do you need? You need a car? You need this, you need that". She can't accept, she can't talk to me about my breast</p>

Janice et al. - 2011	I think he just feels bad because he lost my mom to breast cancer and I think maybe his having to watch me suffer through it—it made him angry with me.. He’s done and said things that have been very hurtful. He says things like I use cancer to get what I want or I think that because I have cancer, like nobody can tell me “no” about anything.
EM07 Bhattacharya, Gauri - 2012	<p>Fear of Failure</p> <p>adopting the T2D self-management guide- lines regarding diet, physical exercise, and medication adherence all at the same time</p> <p>the women described feeling alone in their daily efforts to follow the guidelines regarding food pat- terns, physical exercise, and medication compliance. Men not only felt depressed because they felt alone in making these changes; they expressed more concern that their family would treat them as lifelong sick persons</p> <p>“How can I say I am now sick for my whole life? They will think who will take care of this man?”</p> <p>My family is young—young kids, wife. They may not say much but think I am a sick person.” On second thought, this man continued: “I have some money—it would help me for a while, I guess.”</p> <p>A 68 year old single man who was recently T2D-diagnosed and lived with his daughter’s family sadly summed up: “You are lonely—when no family, and alone—within your own family especially when you are old and sick.”</p> <p>doubt about the benefits of medically recommended lifestyle changes.</p> <p>skeptical of the medical care system.</p> <p>The majority of the women and men trusted that God is their healer. Who always takes care of them in their challenging life situations. This belief in destiny reduced their self-motivation to make changes by themselves. As a 55 year old man explained: “I have faith in the Lord, my wellbeing is in His hands. He saved me all the time. If you have faith in the Lord, the Lord will show you the way.”</p>
EM08 NANTON, V. et al. - 2011	<p>their knowledge had been vague.</p> <p>Most of us didn’t get information before you got pros- tate. Most of us didn’t know about prostate, what it’s for you know</p> <p>Though men had asked for practical support in terms of incontinence aids following the immediate post- treatment period, their supply had been inadequate or slow to materialise. This has been a cause of stress, embarrassment and inconvenience to many.</p> <p>Well, going back some time ago – that’s going back nearly over two years now. I went up the advice bureau, you know?: And all they did offer me was a little food and things there and after a couple of weeks I said no, I didn’t want . . . because it didn’t suit me</p> <p>..... Well I think that is a failure man, and I don’t know that they would be like that. (Mr J)</p> <p>Widowers, particularly those who were also very elderly and frail, and those with wives who were unwell them- selves appeared very isolated with few social contacts. In several instances, these men demonstrated particular problems coping, through lack of knowledge of services and the complexity of referral procedures</p>
EM12 Wiljer, David et al. - 2013	<p>Participants reported encountering certain barriers that prevented them from taking charge in managing their own care, such as difficulties prioritizing and having other family responsibilities.</p> <p>Participants addressed their physical needs as an obstacle to managing their disease, health and well-being. Issues regarding how to handle their fatigue and lymphedema were reported</p> <p>Nutrition was identified as an area not ade- quately covered by the consult.</p>
EM13 Kowitt, Sarah D. et al. - 2015	<p>PSs reported that peers confided in them about a variety of stressors that affected their emotional well-being and diabetes managemen</p> <p>psychosocial issues, such as deportation of a loved one, domestic violence, loneliness, and financial strain; psychological concerns, such as stress, anxiety, and depression; and other health conditions, such as high blood pressure and arthritis</p> <p>. Similarly, in North Carolina, PSs frequently mentioned that it was not their position to tell a peer what they should or should not be doing; instead, they viewed their role as assisting peers in setting mutually decided goals.</p>
EM15 Taylor, Francesca et al. - 2016	<p>established kidney failure engen- ders an altered conception of self in relation to others; patients and carers mentioned having to adjust their lives and lifestyle and how this changed relationships with family members, friends and work colleagues</p>
EM16 Vries, D. H. de et al. - 2016	<p>Participants also mentioned experiences with rejection within health institutions, dentist prac- tices, and even when trying to obtain a mortgage for purchasing a house. One out of five respondents who did disclose felt that they have been discriminated against or excluded</p>
EM16 Vries, D. H. de et al. - 2016	<p>“After I told him about my HIV-positive status, he didn’t want to see me or have sex with me anymore”</p>
EM16 Vries, D. H. de et al. - 2016	<p>he was not welcome in the home of some friends anymore after telling them about his status, while the dentist refused to treat h</p>

	<p>Self-stigm</p> <p>"[Due to my HIV] I have the feeling that I am worthless" (</p> <p>the largest gains can be made by disclosing to employers, colleagues, and children in the household. Also notable is the number of discriminating responses within the health professionals (32%). This is less for women, yet more among Dutch or Western respondents (relative to minorities).</p> <p>Qualitative data shows how the impact of stigma on disclosure also negatively impacts other self-management strategie</p> <p>an effect of nondisclosure due to (the fear of) stigmatizing attitudes seems to be that PLWHA become less adherent to their medication because they, for instance, do not want to take their medicines in front of other people. O</p> <p>"I do not feel good, I am constantly scared to take my medicine when I'm with friends"</p> <p>Selective disclosure can bring one's self-esteem back and empower people as a way to gain social support and be freed from a secret. Yet, stigma influences disclosure negatively as experiences with or the fear of stigma motivates a nondisclosure, both selective or completely. Both forms of nondisclosure create relative silence about respondents' HIV-positive status, which allows the high HIV-related public and structural stigma within the Dutch society to remain existent.</p>
<p>EM17 DiGiacomo, M. et al. - 2015</p>	<p>Another professional stakeholder participant discussed that the women she works with may avoid seeking help or may lie to minimize financial shortfalls when unable to re-fill prescriptions for fear of being labeled and stigmatized.</p> <p>For example, although women may be perceived as more proactive, older generations may feel that the 'doctor knows best' and accept his or her word without question. Depending on the doctor-patient rapport and individual characteristics and skills, women may not feel confident to ask questions during consultation</p> <p>Health professionals may erroneously assume chronic disease sufferers or their caregivers, including those who may be health professionals, have acquired expertise and capacity for self-management throughout the duration of illnesses.</p> <p>most informational resources are in English which makes it very hard for carers from CALD backgrounds to navigate the health system without support.</p> <p>"People who are stuck, like, they migrated 30 years ago and the cultures over there have changed, but they haven't. They're, sort of, stuck in that patriarchal, sort of, mindset." (PS)</p> <p>The disproportionate burden of caregiving on women impacts negatively on self-care</p> <p>caregiver women were less likely to look after themselves, had less time to themselves, and experienced more stress and pressure to meet competing demands. Caregivers often have chronic conditions, yet these were less prioritized in their, and in some cases, other people's views. Participants noted that women may accompany a male partner to a medical appointment, potentially offering advocacy, but the reverse was less common</p> <p>women were seen to be more proactive than men in seeking support for others, but often delayed until crisis point for themselves because they did not want to be a burden</p> <p>The caregiver journey was perceived as an isolated, complicated, and unsupported one. A</p> <p>"...I think women enjoy, very much, that aspect of that personal touch, the feeling of being looked after...</p> <p>High costs of specialist and other appointments as well as associated transport, parking, and meals contributed to financial hardship for women. Caregiving and having a chronic condition impacted on</p> <p>If you don't drive, you know, you can't go anywhere...You got the buses, maybe the bus every three hours they go somewhere, so what are you going to do?" (CM)</p> <p>In cases where there is intimate partner (or other domestic) violence, which was described as under-reported in the study region and represented a significant deficit in relation to needed supportive services, also had carried financial implications for women thinking of leaving a violent relationship.</p> <p>"More likely to be poverty stricken if you go it on your own" (PS)</p> <p>For older women, in particular, who often have multiple chronic conditions, but whom are impacted by social, cultural, sometimes linguistic, and economic contexts that impede care, the silo-structure is a major obstacle.</p> <p>This leads cynicism and loss of trust within the workforce, as well as in consumers, as illustrated in the following excerpts:</p> <p>"I hear all the time of carers try getting domestic assistance to come and get it. Because you do, you ring up, and no one would call, or they've got a waitlist - - - some don't even have a wait list, or then the social worker told me, 'Oh, you've got to ring every month.' So, it's like a big hassle, you know. You may as well clean the house yourself for an hour, rather than sit on the phone for three hours ringing all the service providers." (PS)</p> <p>"People don't understand about respite, what that even means. And even - I mean, in a way we set up false expectations, because we go in and tell them, 'Oh, there's all these services available.'... And then they ring, and there aren't all these services available." (PS)</p>

EN01 Ekundayo, Olugbemiga T. et al. - 2012	being black, testosterone, improper diet, nutrition, lifestyle, beverages, being in a night club all night, not seeking medical examination, inheritance and heredity lack of knowledge of symptoms low levels of resource utilization lack of knowledge; lack of ability to pay technology barriers lack of screenings, Don't know how to prevent unaware of the location of facilities Lack of knowledge
EN02 Browne, Annette J. et al. - 2012	security guards routinely deal with behaviours in ways that often resulted in escalating frustration and aggressive behaviours, and ended in dismissal or banning of patients and police involvement people with trauma histories often experience mistrust, building trust is critical to sustaining connections and a sense of personal safety inadequate social housing
EN05 Graffigna, Guendalina et al. - 2014	Food is strongly emotional and at the representational and symbolic level
EN09 Flournoy, Minnjuan W. - 2011	Lack of sustainability/funding issues Cost of care High provider turnover The limited number of dental clinicians was cited as a challenge to continuously engaging patients in care Frequent breakdowns and issues with the equipment further delayed service and discouraged patients from continuing to return for dental care. the mobile unit itself malfunctioned a number of times and the staff indicated that providing services at those times would endanger the safety of the patients, I think it's been a big help but my concern is what happens when the grant runs out. My concern is what happens if it doesn't sustain itself, the cost of care, which made them consider not returning for service she said something about don't forget to bring the fee or something like that in the message. I was confused because I remember when the program started, I didn't have to pay for service I wasn't too surprised when they started charging. It wasn't like we had to pay the full cost I don't have dental insurance, and I surely can't pay out of pocket
EN14 Hirjaba, Marina et al. - 2015	Diabetes can cause difficult situations at work. For example, if I have problems with my blood sugar balance, I find it difficult to manage if work colleagues or my employer are not understanding and supportive.
EN17 Bailey, Kenneth Chase et al. - 2014	Housing situation the environment not being conducive to healthy living the poor infrastructure (lack of sidewalks, grocery stores/restaurants, recreation facilities, parks and trails), the composition of the neighborhoods (subsidized housing, vacant lots), and lack of safety (drug houses, vandalism, burglar bars, fear of walking alone at night) are not conducive to healthy lifestyle.
EN18 Mitchell-Brown, Fay et al. - 2017	cost of health insurance For all my visits and prescription, I pay from my own pocket. This is what makes me upset. Diabetes is a new concept for the Hmong people lived in Laos, our elders never had this disease, b
EN19 Garcia, Jonathan et al. - 2015	The risk of violence resulting from "internalized homophobia" in discreet spaces such as parks contributed to context that facilitated "rushed sex" and drug use. In these spaces, men seemed to place higher priority on avoiding arrests by the police than they did on avoiding the other dangers of those spaces (namely, physical violence, sexually transmitted infections from unprotected sex) "Cops believe if you have condoms on you, you're a sex worker" The general mistrust of law enforcement and knowledge that carrying condoms could be used against them in court effectively deterred several participants from carrying condoms. they no longer attended church because of outspoken preaching against homosexuality, feeling they were not "part of" the community b
EN23 Davies, Freya et al. - 2014	Dutch FGD3: General Practitioner 5: "Some people get an exacerbation on Friday evening and they are afraid to call, they wait and wait and on Monday they call, they are so deep in the exacerbation that it takes a long time before their condition improved again." General Practitioner 3: "With those people you perform self-management, with others you don't." 3d Norwegian FGD1: General Practitioner 3: "But it's quite clear that one has to consider such situations, that they live far away, if you get a call at the practice, from the east side of town, far away, right, and suspect that it can be something

	<p>like this it would be good if they had some drugs at home.”</p> <p>General Practitioner 1: “Yes, and it’s windy, they need to take the boat and stuff, it’s closed, there is danger of avalanches and many other things like that have to be taken into consideration’</p> <p>self-treatment was not needed because patients already had timely access to assessment by a clinician or that self-treatment would not be needed if access to GP care was better</p> <p>only patients who could understand the correct use of self-treatment should be offered rescue pack</p> <p>concerns that the required level of understanding would not be found in all COPD patients.</p> <p>struggle to access prompt treatment for logistical reasons</p>
<p>EN24 Powell, Rhea E. et al. - 2016 6</p>	<p>social determinants of health that limited their patients’ ability to manage their health including: insurance issues; financial barriers; mental health and substance abuse; and housing and transportation need</p> <p>lack of insurance</p> <p>unaffordable</p> <p>for patients without insurance, access to primary care was restricted due to excessive wait times and limited provider availability</p> <p>many of their uninsured patients often chose to go to the emergency department (ED) for care because of faster care and more available services.</p> <p>inability to pay outpatient and medication copays</p> <p>“I had a patient a few days ago who didn’t want a home visiting nurse to come out to check his incision because he couldn’t afford the co-pay.”</p> <p>If you don't have insurance, you go to the emergency room and you use the emergency room as your doctor, your clinic.</p> <p>the emergency room have the services right there and they don’t have to wait like with a clinic you have to wait.</p> <p>So someone is perhaps not able to buy their insulin because they need to have 10 percent to get their son’s bail – to set the bail... I’m just saying that the problems are so pervasive from violence to depression to living in situations that are just – there isn’t any one service that’s gonna fix all this</p> <p>[Primary care provider] implies stability. A [primary care provider] implies that the rest of your life has some degree of continuity. Sometimes you can’t – you can’t even control it.</p> <p>...so they feel that’s their life. It’s constant crisis</p> <p>They do not understand the importance of having a primary care physician</p> <p>there’s no clinics nearby. There’s no pharmacies nearby. There’s no people walking around on the streets that are talking about their healthcare....</p>
<p>EN25 Robinson, Nicola et al. - 2015</p>	<p>they’re not accessing services, [PPE can find out] why they’re not and how services could be made more attractive to them</p> <p>Overcoming the barrier of stigma</p> <p>stigma is worse for ethnic minorities, where sexual health (or PPE) may not be acknowledged</p> <p>in some cultures it’s more difficult to come out, there isn’t the listening, talking therapy concept.</p> <p>I had an Asian patient’s mother the other day say ‘it doesn’t happen in our community’,</p>
<p>EN29 Richardson, Lorilei M. et al. - 2016</p>	<p>“I’m focused on pain, I’m trying to relieve the pain. Everything else is secondary”</p>
<p>EN30 Cook, Erica J. et al. - 2014</p>	<p>It is a paid number it puts people off</p> <p>f you are really poorly and you have a mobile phone and you have no credit on there then you can’t ring NHS Direct but you can ring 999 and get an ambulance to you for free</p>
<p>EN32 Hogden, Anne et al. - 2012</p>	<p>poor quality information compounded patients’ difficulty accepting the inevitable nature of their condition</p> <p>when patients were able to access specialized services, physical resource constraints compromised care options. Participants reported frustration with long waiting times for equipment</p>
<p>EN34 Natale, Anthony P. - 2009</p>	<p>This was linked to a number of factors contributing to HIV prevention exhaustion including advancements in antiretroviral treatments for HIV disease, the life expectancy of those living with AIDS ever expanding, development of a club drug culture among MSM who socialize in those venues, and a generation of YMSM who, because of always having had HIV/AIDS in their lives, attribute a different meaning to living with the disease</p> <p>it seems like something that we have gotten used to, like an old pair of jeans.</p> <p>limited access due to clinic or agency hours, lack of transportation, waiting lists and homelessness</p> <p>traditional social service agencies that provide individual or group supports do not meet their more immediate needs such as housing, food, health and mental health care, or substance treatment as evidenced in this next passage</p>
<p>EN35 Gien, Lan et al. - 2017</p>	<p>foods mentioned in the internet are not available locally “Some of the things they suggest you eat is things that I haven’t heard of”, “You’ll never find it (in this province)”.</p> <p>Rural residents may also feel like outsiders in city hospitals and clinics and may be reluctant to visit them</p>

	<p>the rural culture of autonomy, self-reliance, together with low health literacy may have contributed to access barriers</p> <p>cost of DM, due to having to pay for medications, equipment and materials for blood glucose self-monitoring</p> <p>high cost of groceries</p> <p>no private health insurance</p> <p>For rural residents, physical activity varies depending on season.</p> <p>long winter, however, exercise meant walking around their neighborhood which was difficult due to unsafe icy, slippery roads and strong cold wind</p> <p>with limited income, they could not afford having exercise equipment such as treadmill or stationary bicycle</p>
EN36 CLOCHESY, JOHN M. et al. - 2015	<p>I don't want to schedule another appointment because the next appointment is going to be another \$200</p>
EN37 McCabe, Catherine et al. - 2014	<p>their travel was now restricted and nonspontaneous particularly for those who required continuous oxygen therapy and needed to carry an oxygen tank.</p> <p>"If I go away I've got to have the c-pap machine, the nebulizer and the portable oxygen concentrator. I mean that takes up a suitcase, you get all that lot together.</p> <p>The loss of employment was devastating for younger participants in this study and contributed to decreased confidence in self-managing</p> <p>All participants received fixed income benefits and/or a pension as their primary income and commented on the difficulty of living on a minimal budget that does not provide flexibility to support areas of change</p>
EN39 Durme, Thérèse Van et al. - 2014	<p>Because emergency rooms are open 24/7, where payment is delayed, in most cases, a hospitalization can be an easy solution for a crisis situation at home</p> <p>long delays (1) for specialist consultations, especially in remote areas (e.g. ophthalmologists) and (2) nursing home</p>

Table 22 - How participants heard about interventions, technologies, etc

CO06 Graves, K. et al. - 2011	<p>"importance that family plays in the lives of African American women" adding that "I think that... they can easily recruit for social support from other women</p>
CO36 Wilkinson, Emma et al. - 2014	<p>the only way we know is because my brother-in-law is a doctor and he told us</p> <p>family members were a good source of information</p>
EM03 Goldenberg, Shira M. et al. - 2016	<p>HIV testing offered through research studies</p>
EN01 Ekundayo, Olugbemiga T. et al. - 2012	<p>churches</p> <p>Announcements in paper</p> <p>Information, Technology, Customer Service and Referrals</p> <p>Free screening,</p> <p>Vocational rehab</p>
EN30 Cook, Erica J. et al. - 2014	<p>. Many 'users' were directed to NHS Direct through their GP answer phone machine when they had phoned their surgery out of hours.</p> <p>When I first called it I had called my doctor and the doctors surgery didn't have an out of hours so they actually give you the NHS Direct number so that's how I knew the number</p> <p>'I think it was from the midwife</p> <p>the service advertised through yellow pages</p> <p>local level advertising</p> <p>a number of participants recalled a small credit card leaflet which had the telephone number on which participants could keep in their wallet.</p>

Table 23 - Self-management facilitators

CO01 Sacks, A. Abt et al. - 2016	<p>Doctors informed patients about the different treatment</p> <p>If you want to be an active part of the treatment, you obviously need a broader education. Of course you have to trust the doctor but you also have to look around yourself and not only make sure that what they are giving you is the best thing and that it's suitable for you</p> <p>you also have to accompany the doctor</p> <p>She normally explains the different treatments, the options available and the reasons why I should choose the one she considers more suitable for me</p> <p>patients are perfectly able to make decisions for ourselves and that we need to do it</p>
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	Risks and benefits of the different treatments, procedures for each one and estimated time for these if I got the information beforehand, let's say, a week before the next appointment, I think over and over again whatever little I know, talk about it, look it up, search it on the Internet to see the pros and cons
CO02 Dellasega, Cheryl et al. - 2011	<p>the MI intervention encouraged them to be responsible for their own care. In this way, they disclosed more openly and also took ownership of the lifestyle changes they needed to make in order to be healthy.</p> <p>physicians, nurses, and family members could not "force" them to change their behavior nurse as a resource.</p> <p>nurse often helped them reestablish priorities.</p> <p>Collaborative action planning and goal setting</p> <p>we'll work together to set goals, together, and I find that very helpful."</p>
CO06 Graves, K. et al. - 2011	We're talking about future cancer risk, not something we know about right now. So, I think sometimes it's perceived as not absolutely necessary
CO07 Alexander, Stewart C. et al. - 2012	<p>over 97% of hematologists–oncologists, providing at least one explicit recommendation ('We should get started with thalidomide and dexamethasone in the next few weeks')</p> <p>Physicians discussed treatments in relation to both curative goals (72% of conversations) ('what takes to cure it is a bone marrow/stem cell transplant and with eight brothers and sisters, you are likely to have someone who will be a match for you') as well as extending life (22%) ('that is a condition we can manage for many, many years with these drugs').</p> <p>Discussions about clinical trials were common</p> <p>alternative medicine was discussed</p> <p>checked patient's understanding of information</p> <p>Discussion about patients' preferences for their role in decision-making</p> <p>Discussion about treatment impact on patients' quality of li</p>
CO08 Dowling, Joni E. - 2010 CO08	<p>relied on the Internet as their primary resource when seeking information to assist them in making decisions about their care</p> <p>sought a second opinion, considered the peer-review process of another hospital as a second opinion, or changed physicians when they were dissatisfied with the care they received</p> <p>used the Internet to assist her decision making. In her research, she found a test called CYP2D6, Cancer Society (www.cancer.org), Breast Cancer.org (breastcancer.org), Susan G. Komen (www.komen.org), and Young Survival Coalition (youngsurvival.org), to get information to assist them in making decisions. Y</p> <p>We checked with different oncologists in the area to verify what kind of treatment they would do</p> <p>wished for a list of recommended Web sites to assist women in the decision- making process</p> <p>As part of the decision-making process, the women sought additional information by purchasing books on breast cancer, visiting libraries, researching information specific to their type of breast cancer on the Internet (71%), networking with other women like themselves (94%), and getting second opinions (47%) when needed. In addition, if their cancer treatment centers lacked services they needed, they (53%) sought out treatment centers providing such services.</p> <p>interwove rational and emotional thoughts with objective and subjective information to make an informed decision about their care, using their authentic voice.</p>
CO09 Laws, M. Barton et al. - 2012	<p>Yet another had decided to stop altogether for some time, until her T-cells are depleted, with her doctor's knowledge but disapproval.</p> <p>. . . So I think a doctor should . . . be more professional, let you know what the side effects are . . . because sometimes the doctor himself, if your side effects are too strong, he'll take you off, but you need to discuss tha</p>
CO11 Meyer, Samantha B. et al. - 2012	<p>higher SES participants in primary prevention were found to be more questioning of medical advice, and less likely to blindly trust</p> <p>When asked if he trusts his GP he replied: 'I got to learn to trust him' and that his trust developed over time rather than being blind.</p> <p>higher SES) is more likely to question the ability of his physician before trusting.</p> <p>she has reservations about trusting all physicians so she specifically chose to see a physician she trusts.</p> <p>each of them individually needs to earn her trust. Similarly, M6 (aged 69, higher SES) said that he trusts his GP and cardiologist because they earned his trust</p>
CO13 Venetis, Maria K. et al. - 2018	<p>although some language in this example is associated with impersonal information provision, we can see that there is markedly less than within Excerpt 1, and that there are increased causative statements that serve to explain why the patient should pursue a certain treatment plan.</p> <p>treatment decision-making interaction is also a context of high informational speech in which providers may describe the tumor and its characteristics (i.e., hormone receptors, stage), outline treatment options, and discuss tracks for surgical outcomes and recovery per treatment options. In short, there is great potential for providers to relay highly informational speech, and it follows that those linguistic features that are markers in informational speech would be present</p> <p>these findings suggest a contradiction to contemporary guidelines that urge providers to "limit the amount of information provided" (Weiss, 2007; p. 29) in order to increase comprehension and health literacy.</p>

	<p>Although this recommendation may provide utility in some medical contexts, it appears that within the breast cancer surgical treatment decision-making visit, patients prefer greater information shared knowledge</p> <p>impersonal focus to the discussion of patient's condition and treatment options</p> <p>focuses on processes related to the diagnosis and treatment</p> <p>impersonal language in discussions of the patient's treatment options may allow the patient to focus more objectively on her options and thus leave her feeling more empowered</p> <p>when the provider uses impersonal language this signals that the procedure is routine for the provider, and the patient's condition is not one that is more challenging or more problematic than other similar diagnoses</p>
CO14 Hersch, Jolyn et al. - 2013	<p>I'm surprised there is overdetection, but I don't think it will really change my view</p> <p>I still think the deaths are high, so I prefer taking the risk</p> <p>"If you were diagnosed you'd really go into what treatment involves ...</p> <p>I'll still go [for screening]. ... Surgery's okay too, but ... anything else being needed, any chemicals to be put through my body ... then that's where I stop and think and look at the statistics."</p> <p>Some participants felt that this knowledge might also give such women more of a sense of control and reduce the pressure to follow a predetermined disease management pathway.</p> <p>Others felt that it was good to know about overdiagnosis in order to be able to make informed decision people should be made aware that the information is there if they would like it ... this might help you make a decision</p>
CO15 Hart, Ruth I. et al. - 2017	<p>Interviewees largely valued the prompt to reflect on their current practice (i.e. efforts to maintain routines despite fatigue, or to manage fatigue): It is useful now and again just to ... think about it and maybe analyse it, analyse what you're doing, and if there is any, any changes that you can effect, because you tend just to go on with the same thing.</p>
CO19 Brez, Sharon et al. - 2009	<p>"Self management" abilities</p> <p>alignment of "patient self management expectations" and treatment goals</p> <p>This was described as patients taking greater responsibility for self monitoring "...they take charge and understand what is a good acceptable (blood glucose) level, what is a hypoglycemic level, when should they be going to the emergency room when something isn't quite right..."</p>
CO20 MacDonald, Kath et al. - 2015	<p>Negotiating care was witnessed frequently</p> <p>were observed as being actively engaged in decision-making in the consultation</p> <p>coping</p> <p>Negotiation</p> <p>Expert patient as navigator</p> <p>Emotion work (voicing cues and concerns, agendas, prioritising)</p> <p>self-management practices</p> <p>requesting result</p>
CO22 Smith, Sian K. et al. - 2008	<p>struggled to understand that it was not promoting acceptance of screening, but facilitating informed choice</p> <p>higher literacy participants seemed to understand the nondirective nature of the DA more readily.</p> <p>You can arm yourself with some information to go and ask your doctor</p> <p>A very good illustration...doctors talk to you about large intestines, small intestines and if you dont have a medical background, you have no idea exactly which bit of you anatomy they are talking about.</p> <p>You really want to know what cancer is, you want to know where it is situated, how it affects you.</p>
CO27 Dolce, Maria C. - 2011	<p>Changing doctors was the result and probably a life-saving decision</p> <p>[I] faced surgeries with a very good idea of what was to happen, sure did not know this prior to first surgery</p> <p>Participants exercised their own power or will to influence and control care decisions during survivorship.</p> <p>sharing of power and responsibility with their healthcare providers in making healthcare decisions.</p> <p>Participants provided examples of collaboration resulting in changes in their plan of care.</p> <p>Confrontation: Participants exercised power through direct confrontation with their healthcare providers, which included behaviors such as questioning, persuasion, and coercion. Armed with the "right questions to ask," survivors and caregivers challenged healthcare providers</p> <p>influenced their care and treatment plan by exerting persuasive power</p> <p>Many were able to "insist" on treatments, "demand" procedures, and "push" for care</p> <p>Becoming expert: Participants exercised power by becoming knowledgeable about treatments</p> <p>I was then more proactive in my care, and switched specialists.</p> <p>I did my own research online and then consulted with the members of my list. I knew in my heart that this was not the right treatment for me, not yet anyway, when there was something better out there</p> <p>Endorsement: Participants exercised power through endorsement. Online communities served as a vehicle for endorsing preferred healthcare providers</p>
CO29 Reimann,	<p>inform the patient about decisions</p> <p>to (transparently) involve the patient in the process of examination and treatment.</p> <p>the patient can open up to entrust the doctor with all of the necessary information</p>

Swantje et al. - 2010	appropriateness of the treatment (e.g. medications without or with only minor side effects, no excess treatment, individualized medical treatment, no doubled examinations, awareness of price). the doctor includes you in decisions about your care and treatment involvement in the treatment
CO31 Zulman, Donna M. et al. - 2015	self-management routines
CO35 Goddu, Anna P. et al. - 2015	makes you feel stronger because by you looking at that video and you listen at the doctors talking and then you looking at the patient . . . it makes me make better decisions for myself.” [Film]
CO36 Wilkinson, Emma et al. - 2014	use different ways of dealing with it, perhaps not such a standardised rout
CO37 Taylor, Elizabeth et al. - 2014	Setting goals Assessment Treatment successful goal-setting involves negotiation and education Therapists reported favouring a functional (rather than impairment based or table top) approach to assessment
CO38 Duineveld, Laura A. M. et al. - 2016	GPs discussed patient’s preferences regarding the degree of the GP’s involvement in order to personalise their contact. GPs wanted patients to participate in decision-making. They suggested providing patients with the possibility of arranging their own care, by defining individual goals during rehabilitation and stimulating patients to decide which supportive care they desired. To what extent do you want to go on in case of recurrent disease? What do you want in that scenario and what do you not want? You can also think of: which sort of care do you desire and what type of care not? (
ED14 Vega, Gema et al. - 2014	“They been so nice to me, so nice. Wonderfu Well, hmm, truth be told, hmm, the interviews I had with the cardiologists, after, after surgery, hmm, added nothing. Um, that might seem harsh. I’ve had prescriptions, ECGs, blood tests, and with that I know my triglyceride levels, and good and bad cholesterol, and if my blood sugar level is too high or not right, but, um, I don’t need a cardiologist for that. For that I could go to a chemist’s and they do it for me. What I mean is that I haven’t had guidance, right, on how, how to make the most of my, umm, my personal choices and make them more effective for a healthy lif
ED15 Goebbels, Adrienne F. G. et al. - 2012	The counselling sessions also helped respondents to set more concrete and realistic goals for LBC. Together with the counsellor they broke intended lifestyle changes down into smaller steps that can be implemented more easily. Respondents described for instance that as a first step to LBC they started to rearrange their daily life schedules to create rest and time for themselves.
ED16 Wright, Nicola - 2013	instead of looking at it from the negative I turned it round to look at the positive because you have to make decisions for yourself at the end of the day (I have actually learnt that you need to action plan what you are going to say to your GP before you go. I am more confident about taking control of the conversation with the Doctor than letting the Doctor take control. I want to be in charge of what is being said and what is going to happen to my medication and things like that more able to take control of their interactions with medical and other healthcare professionals
EM04 Boise, Linda et al. - 2013	They have to send us to a doctor who understands how Africans live . . . they have to recognize they have the limitations.
EM06 Phillips, Janice et al. - 2011	To have my husband go with me to all the appointments; and there is something to be said about when you’re the patient, you are so distracted and scattered brain—as a medical student, you hear all this, that they don’t hear half of what you say—and you leave and you’re like, ‘they didn’t tell me that?’ ‘Yes, we did,’ you just didn’t, couldn’t hear. So to have someone else who was there with me to ask questions that I would have ask if I were in my right mind, Knowing that my sister has the gene. This is something that I need to be more serious about, that’s another reason why I came on in [to be tested]. I have a three- year old daughter that I want to see grow up and graduate from college and high school. I want to be able to see her kids and my grandkids, you know He was not a good doctor to me.... He pulled out the freaking algorithm and showed a flow chart like, ‘Oh, since you have this, then we will do this.’ And I’m like, ‘you’re going to boil my life down to a flowchart?’ So it didn’t make me feel like he was really interested in my recovery; so I didn’t go to him. So I went and got my second opinion from another lady

	<p>I would like to get information specific to the younger age bracket, like the age bracket of people that aren't eligible for mammograms and like, I don't know if this is an option, but lifestyle adjustments or things that could be done to help reduce the risk of getting cancer</p> <p>I think more women—definitely younger, black women—need to pay attention to their bodies. They need to know their bodies; know what's changing and not be afraid to say, 'hey, something doesn't feel right.' Because like I say, especially working in the cancer unit, we are getting younger women. They will come in at 18 and 19, 20 and once they come in, it's too late. We are going to make them comfortable. We're going to try what we can, but the cancer is rampant and that's because you choose—your body told you something was wrong and you choose to ignore it. And I would just like women, especially the younger women not ignore.</p>
EM08 NANTON, V. et al. - 2011	<p>Traditional remedies had played a central part in the family armamentarium. Men described bitter tasting bush and herbal teas (black tea, black mint, jack in the bush, fever grass, cerasee) that were prepared by their mothers, to be taken both as preventative and curative measures. All except the youngest two men continued to use these,</p> <p>information was important (if you get the information it helps you to cope) only the three youngest had actively questioned their doctors, though several had sought information from books and the media.</p>
EM09 Grande, Stuart W. et al. - 2013	<p>among friends they understand a certain level of "face saving" that must occur in order for others to really intuit the importance of making better decisions.</p>
EM10 Peterson, Jennifer L. et al. - 2012	<p>I've talked one-on-one and in a support group but I mean, in a support group you get a lot more feedback from other people "Oh well I've been through that" or "this is what I did" versus one-on-one the person says, well you know, either "I understand" or "I don't." So I think with the support group, there's a lot more feedback and a lot more people throwing stuff out there than just one other person's opinion – but both are valuable.</p>
EM11 Nota, Ingrid et al. - 2016	<p>"The rheumatologist made that decision." But shortly after, she showed to have (obliviously) influenced the decision and decision-making process: "And he was very much aware of the fact that I did not want prednisolone." [Female, 41 years].</p> <p>Only a few respondents (n=3) wanted to decide mostly by themselves. One patient stated that she herself feels her symptoms best: "Well, for example, if I get side effects, then I believe I should be the one to decide whether or not to continue taking the medication, because I feel my body best." [Female, 62 years]</p> <p>"I have a family and I do not want to be hospitalised for a few months. I weigh up the pros and cons, I decide that." [Female, 41 years]</p> <p>"I am in control over my own body. If there is a decision at stake, I decide by myself. I do not need anybody else to help me." [Female, 74 years].</p> <p>Most respondents (n=17) preferred shared decision- making (SDM), because it reflects a good relationship with the doctor,</p> <p>I want to share in the decision-making process. That he listens carefully to what you have to say and that you listen to his arguments as well. And that you can say anything, even small things, without feeling a bore. That's when you have a good relationship." [Female, 60 years].</p> <p>expertise of the doctor highly but wanted to be a part of the decision-making process because they themselves feel their symptoms best, wanted to have some level of control or wanted to critically evaluate the impact the doctor's advice would have on their personal situation and discuss this</p> <p>"I want to share in the decision-making process. As a patient, you should follow the doctor's advice, you should not say it is nonsense, you cannot do that, but I do critically evaluate his advice. [...] And if I do not agree or have questions, well, then I discuss this with him." [Male, 56 years].</p> <p>It is about you, you are responsible for your own body, but because you do not have the knowledge, you also depend on the doctor, so he needs to be responsible as well. So you share the decision-making." [Male, 50 years]</p> <p>Although they did prefer SDM, they wanted the doctor to be responsible for the outcome of the treatment. "He is the expert and, in the end, it's his responsibility. He is the one who is truly responsible, but we decide together." [Fe- male, 54 years].</p> <p>Some respondents noted that their preference regarding involvement in medical decision-making depends on the occasion.</p> <p>Well, with medication, [...] you always have something to say about it, because you do not have to take them anymore if you do not want to. But if she tells me about a surgery, [...] I would say I would first like to wait a little longer and think about it. But that, to me, is of a different order than medication." [Female, 61 years]</p> <p>"Starting [medication]. Because the medication can be quite intense, it is very important to me to think about it: Do I want this? A</p> <p>When starting medication I prefer to share in the decision-making process. Increasing the dosage is something I want to decide myself, as I'm the one who can best determine how severe my pain is. And the doctor decides if the dosage needs to be decreased, because he/she understands what my blood level results mean.</p>

	<p>It also depends on how you feel. Actually. If you feel fine, you think: Say whatever you want, but I do not need it, and if you do not feel so good, then I gratefully take the advice." [Female, 41 years]</p> <p>Last year I was in so much pain. My knees were killing me. I called the doctor and like a drug addict I begged for an injection. Normally I wait until the next check-up and the blood level results, but now I took control." [Female, 54 years]</p>
EM12 Wiljer, David et al. - 2013	<p>he effectiveness of using eCancer as an interface to creating a survivorship care plan (results reported in another manuscript) was helpful for some participants with their feelings of 'being rushed' by providing structure and keeping the clinician and participant more focused on the conversation</p> <p>Participants reported feeling comfortable sharing their opinion and discussing aspects of their health condition and trajectory of care with the clinician.</p> <p>"...that encourages me quite a lot to seek out the program and find out more about it..."</p> <p>we went beyond cancer...[talked about] work stresses and return to work...some help you can get for return to work strategies before you get into that..."</p> <p>...fatigue is a huge issue so [the clinician] mentioned that...I was complaining that I was somewhat brain dead...[the clinician] mentioned...good recommendations..."</p> <p>"There's a lot of confusion about taking care of yourself and how best to do it... Nutrition I feel like is a big one that was not covered."</p> <p>"We talked about groups and clubs, always looking for speakers and that type of thing. I think [the clinician] had a clear understanding of where I was coming from at that point. [The clinician] really addressed that..."</p> <p>"I felt, emotionally, that I was stronger and that I have a lot of sources that I can go and follow. I can finish this journey."</p> <p>"I felt very empowered actually."</p> <p>"...it could be helpful to you and it could make you feel in charge of what you have to do."</p> <p>"I just find that everything was so helpful and relaxed. I felt so relaxed. I didn't feel like a typical, sort of, doctor's appointment. It felt like at this point, there was hope."</p> <p>"...the opportunities in the community for helping different areas...really good to know that they're out there...I feel like it's important to know that they're there...a lot of patients do want to use those support systems."</p> <p>Participants believed the SC provided abundant and useful information resources available to support their health condition and treatment options and reported that it enhanced their understanding and awareness about their diagnosis and treatment option</p> <p>The SC helped participants to identify needs in the physical, psychosocial and emotional domains. Many participants were unsure of their additional needs other than standard medical care. Participants expressed their needs for sufficient support in the psychosocial domain and expressed the need for help in coping with their emotions accompanying their illness, treatment and further care.</p> <p>Participants reported the SC helped them become more in charge of managing their own care by providing them with the resources, information and the organizational skills that they thought necessary to help them through their cancer journey. Participants reported feeling more empowered and hopeful.</p> <p>A majority of the participants mentioned if the consult was held at the beginning of their cancer journey, they would have found it much more useful.</p>
EM15 Taylor, Francesca et al. - 2016	<p>Having choice and control in relation to certain aspects of the timing and delivery of formal peer support were important considerations for some interviewees.</p> <p>greater choice, control and ownership</p>
EM17 DiGiacomo, M. et al. - 2015	<p>"Let's face it, if you've got a female GP, you're lucky really...I find women are better at listening than men" (CM)</p>
EN01 Ekundayo, Olugbemiga T. et al. - 2012	<p>annual screenings</p> <p>screenings for African Americans</p> <p>increase health literacy</p> <p>legislative and policy advocacy</p> <p>Service education,</p> <ul style="list-style-type: none"> • Health literacy,
EN02 Browne, Annette J. et al. - 2012	<p>leaders negotiated for physicians to be paid by salary rather than fee-for-service to enable their participation beyond direct patient care in interdisciplinary meetings and case conferences</p> <p>Engage in decision-making on the basis of critical analyses of power differentials, flattened hierarchies within interdisciplinary teams, and shared leadership approaches</p> <p>implementing clinical practice guidelines that are flexible, dynamic and can be adapted to the person's life context, personal circumstances, and highest priorities</p>

EN03 Locock, Louise et al. - 2011	Access to better information or help with decision-making
EN05 Graffigna, Guendalina et al. - 2014	I would definitely have appreciated some counselin I would appreciate having the opportunity for a more relaxed encounter
EN06 Walters, Chasity Burrows - 2013	shared responsibility does not imply an equal sharing "I think everybody should always take some responsibility for their own welfare to the extent they are able. their involvement in protecting their safety was intuitive. using common sense, participants indicated patients should practice the same behaviors while hospitalized as they would otherwise
EN09 Flournoy, Minnjuan W. - 2011	allowing patients to ask questions before, during, and after clinicians shared in depth information
EN10 Brooks, Fiona - 2008	The council engaged in a wide range of activities, from commenting and advising on documents, establishing working parties on specific topics, to membership of hospital multi-disciplinary groups such as involving service audits or reviews of cancelled operations creation of shared understandings.
EN14 Hirjaba, Marina et al. - 2015	the opportunity to be involved in their own care, in terms of planning, participating in and implementing disease treatments
EN15 Maten-Speksnijder, Ada J. et al. - 2016	Stimulating patients being actively involved in health assessment sometime Coaching of patients' goal-setting Together they discuss the findings. She had developed a goal-setting coaching programme to encourage patients to think systematically about actions and consequences. A
EN16 Holmberg, Christine et al. - 2015	I'm taking a step. (...) by taking the pills and following it along I feel like, I'm more in control than if I were just standing back waiting and living in fear o
EN23 Davies, Freya et al. - 2014	trust on both sides there are people for whom it's very important to have the feeling, that they can do something by themselves we have to explain it very clearly and in detail, instead of just prescribe it for the patient we prescribe the rescue pack, we need to assess patients' understanding and then prepare the guideline patient education time constraints that made providing this education difficult to motivate patients t
EN32 Hogden, Anne et al. - 2012	Clinicians reported that their aim was to guide the patient and carer through upcoming decisions. They sought to do this in a timely manner, by providing the patient and family with evidence-based information on the available options, in regular discussion of patients' projected health care needs. Practitioners saw their involvement as a cyclical process, responding to recurrent change as the condition of the patient facilitating patient-centered decisions to suit the inevitable changes to patient health and lifestyle. cognitive and behavioral changes impacted on patients' health care decision-making appropriately timed diagnosis and symptom management, access to ALS-specific resources, and interprofessional communication access to specialized services became the next challenge for patients and their primary health care professionals. A well-timed information patients and families should be informed as early as possible about the diagnosis, prognosis, and expected course of disease progressio Decision- making progressed once patients reached some level of acceptance of their condition. "I think that is an obstacle to timely management of patients ... my waiting list is 18 months. N multidisciplinary model of care access to ALS research information clinician education websit collaborative teamwork, effective communication systems which underpinned that teamwork, and evidence-based clinical information sharing of information, monitoring of the patient's condition and providing a coordinated, timely response to changing patient need provision of clear information to health professionals, patients, and families

	structure
	timeframes
	planning with patients;
	clarification of roles and responsibilities
	"I think good decision-making too also comes from being given really good information ... and multidisciplinary stuff, and everyone singing from the same page." (HP12)
EN36 CLOCHESY, JOHN M. et al. - 2015	e asked me what I wanted to accomplish by us meeting. He listens. We don't, even though it's like an hour, I never feel rushed and I just believe that had I not left the other people, I know I never would've found this person. It makes me feel good because things that I had on my mind or needed clarification or answers
EN38 Ross, Fiona et al. - 2014	Feeling involved in my care and in control of myself and my future Service users generally felt positive towards this agenda and wanted to be more informed and engaged professionals considered that in the current climate, they needed to be transparent and auditable It's evolving and we actually get them to sign the care plan and that they understand what's going on a
EN39 Durme, Thérèse Van et al. - 2014	empowerment patient education. patients are better able to express their priorities and preferences, which may not be the same as the ones of the care providers: electronic data should help obtain quality (self-) assessment of care provision. Moreover, linking clinical files with built-in algorithms should support clinical decision-making.
EN40 Rise, Marit By et al. - 2013	dialogue as an interaction between user and provider directed towards enhancing motivation, reaching shared understanding and establishing treatment goals decisions about individual treatment or health-care management together. These decisions were based on reaching a shared understanding of the situation. Patients described the decision-making process as a joint effort necessary to reach good results: shared responsibility being heard have a chance to influence things... a genuine possibility... not only on paper. They perceived patient and public involvement as a possibility to genuinely influence the decision-making process and thereby avoid being pacified or controlled.

Table 24 - Self-management barriers

CO01 Sacks, A. Abt et al. - 2016	My oncologist tells me I am rather a difficult patient because at times I ask her more so many questions that I seem her boss
CO07 Alexander, Stewart C. et al. - 2012	When palliation discussions did come up, they were often discussed as an option if other treatments failed and thus were often discussed very briefly and vaguely. It was rare for patients and physicians to discuss what role patients could play in recovery Quantitative prognostic discussion about mortality without hedging was associated with lower patient education
CO08 Dowling, Joni E. - 2010	the lack of information to be frustrating because physicians asked patients to make massive decisions
CO09 Laws, M. Barton et al. - 2012	Well she wasn't professional in that she didn't get the guy to explain the options
CO13 Venetis, Maria K. et al. - 2018	patients often have difficulty getting their head around is the mastectomy versus the lumpectomy, When placed in contrast with more nuanced language, the use of causal language can be seen as potentially deemphasizing the patient's role in the decision-making process and minimizing their autonomy. Given that patient-centered care stresses the need for patients to feel involved in making decisions for their own care, such overt presentation of reasons in support of an argument may lead to negative perceptions on the part of the patient in terms of the treatment plan.
CO14 Hersch, Jolyn et al. - 2013	The concept of overdiagnosis: How do we know that there are some cancers that move more quickly or become more malignant than others? ... Who determines what's an aggressive and a non-aggressive cancer?" pressed surprise or disbelief at the current limitations struggled with the fact that overdiagnosis cannot be identified at the level of individual patients Turns me off further ... I'm just adding the things that we've learnt together ... and all the doctors not knowing if it is malignant or not "I don't know, makes me a bit scared now to go for a mammogram many women did not seem motivated to make a well informed and carefully considered decision about whether to have screening. Instead they chose to defer engaging in thorough deliberation until they were faced with the relatively unlikely event of being diagnosed with cancer

	suggested providing overdiagnosis information to women only if and when they were diagnosed with breast cancer rather than before screening
CO19 Brez, Sharon et al. - 2009	when patient, PCP, and specialist expectations or understandings of elements of diabetes management were not aligned, participants felt successful discharge could be negatively affected.
CO20 MacDonald, Kath et al. - 2015	I don't want to do it, I've been doing it for years, chose to avoid attending clinic chose to avoid the ward at weekends HCPs in general were less likely to trust YPs' accounts of adherence to treatment
CO22 Smith, Sian K. et al. - 2008	Many lower literacy participants were unfamiliar with the concept of informed choice
CO23 Davies, Jane et al. - 2014	Multiple patients voiced the concern that they were asked to have many blood tests related to their diagnosis of CHB, without receiving adequate explanation of their purpose, and that there was a lack of follow up to receive and discuss the results.
CO26 Wray, Ricardo J. et al. - 2009	informed decision-making was not mentioned in the discussions It is difficult to know whether this is because educators decide that the simpler message of 'Get screened' is more important, or because they are not fully briefed on the screening controversy.
CO31 Zulman, Donna M. et al. - 2015	complicated diets overwhelming patients frequently used a personal health record that was provided by their primary health care system, the value of this tool decreased when patients received care in multiple settings
CO32 Greenhalgh, Trisha et al. - 2010	(0.13%) had activated their advanced HealthSpace account
CO37 Taylor, Elizabeth et al. - 2014	Most therapists said there was no provision for translation of written information, and reported therefore being less likely to provide written summaries of their assessment and recommendations or strategies for self-management. Therapists perceived that goals and intervention often became more family-centred than person-centred. Delivering the subtleties... how to negotiate goals, how to encourage clients, how to sort of allow them to reach their own conclusions... a lot of those kind of counselling and negotiating skills
ED14 Vega, Gema et al. - 2014	the assessment of and satisfaction with care seemed to depend on education level. Patients with lower education levels tended to be more satisfied.
ED16 Wright, Nicola - 2013	screamed at me not only was I a patient they wanted to make me an expert patient. No thanks I want a life
EM04 Boise, Linda et al. - 201	You're trying to explain what is happening to you . . . English may be your 4th language . . . the doctor needs to take the time to review, make sure communication is clear, but that doesn't often happen.
EM04 Boise, Linda et al. - 2013	Doctors often seemed to have minimal knowledge about common diseases in Africa like malaria that might still affect individuals after coming to the United States (1) and to be unaware of traditional health practices or patients' culturally influenced expectations regarding the doctor's role (2).
EM04 Boise, Linda et al. - 2013	language barriers, stress, loneliness, and the lack of understanding of health care providers about African culture.
EM06 Phillips, Janice et al. - 2011	old my fiancé about it. He asks me if I was sure I wanted to know. I told him yeah. But other than that—I told my sister. My sister thought I was too young and that I should've waited... I ask him was he going to come with me, and he told me yes. And he asks me why did I want to know at such an early age. I told him because that was very important and something that I need to know— I had a lot of medical bills, and I still do, because it's like, I'm not going to not go and see my doctors just because I don't have any money. I'm not going to die because I can't pay my bills. Participants expressed concern that providers thought they were too young to have breast cancer. Even for those seeking care for abnormal breast findings, their concerns were not always met with appropriate attention. One participant commented on the watchful waiting recommended for young women with breast symptoms. She noted: She [physician] told me, 'you're a healthy thirty-four year old, see you in five years'... I got on the elevator, went upstairs—at the time I was working in surgery —so I talked to one of our head nurses and I'm like, 'you know, that don't sound right because I think—I know my primary doctor is not going to do a needle aspiration—so I would feel better if I went to at least one of the breast surgeons. Do you have someone that you recommend?' And so, that's how that happened. So I called down to breast, and got setup to see Dr. and met with him
EM08 NANTON, V. et al. - 2011	little information regarding prostate cancer, treatment and side effects

EM11 Nota, Ingrid et al. - 2016	"We do that together. He prescribes the medicine and I take it. [...] That's the way it is. I don't know how else to explain it." [Female, 69 years].
EM11 Nota, Ingrid et al. - 2016	A small but considerable group of respondents (n=8) preferred the doctor to decide about which treatment to initiate. Trust in their doctor and valuing the expertise of the doctor were the main reasons for preferring not to be actively involved
EM11 Nota, Ingrid et al. - 2016	"With medication, you often know what will happen. Surgery is often much more radical to me: Then you need stop your medication, you need to be hospitalised, you just feel much worse. [...] If the time comes that a surgery is necessary, then the doctor can make that decision. Not me." [Female, 41 years]
EM11 Nota, Ingrid et al. - 2016	When asking respondents about how they perceived their involvement in MDM so far, most respondents stated that they had experienced either shared decision-making (n=13) or the doctor making the decision(s) (n=15). One respondent perceived to have decided by herself. Overall, it seemed patients wanted more participation than they perceived.
EM11 Nota, Ingrid et al. - 2016	Doctor does not listen/take patient seriously "I told him: 'I am very tired, though.' And he said: 'Yes, half the Dutch population is tired.' [...] Then I briefly froze. With such an answer, you feel like you're a bit of a complainer." [Female, 45 years]
EM11 Nota, Ingrid et al. - 2016	Doctor does not recognise role of patient
EM11 Nota, Ingrid et al. - 2016	Offers no alternatives "If you do not agree, you say so. But if he then explains it and there are no alternatives, well, then there is nothing to choose."
EM11 Nota, Ingrid et al. - 2016	Immediately rejects the patient's questions or suggestions
	Doctor does not provide adequate information
	Gives too little information "He is very good at his job, but I have to ask him everything, for example when I don't agree with something he says. I really need to drag it out of him." [Female, 74 years]
	Uses difficult language "Then they start using those difficult words at the hospital and I think: never mind, I don't want to hear it anymore." [Male, 50 years]
	Gives too much information "When I was younger they gave me medication and occasionally I heard what it was, but I don't think they properly explained what the side effects were or could be. Now they do, but now it is tough, because I sometimes get medication which makes me think: do I dare to start using this?"
	patient does not want to delay treatment "Medication is prescribed. You want to become well again, so you cannot say: "I do not want it."
	Too little time to decide "It [starting to use methotrexate] is quite a radical decision. So, er, yes, that [the time given to decide] was a bit short."
	Study protocol leaves no room for alternative options "You really do not have a choice in that respect. There is a [study] protocol, and it is not like I can use other medication."
EM12 Wiljer, David et al. - 2013	Some participants felt that they did not have enough time to engage fully in a collaborative discussion with the clinician and felt too rushed
	Participants reported encountering certain barriers that prevented them from taking charge in managing their own care, such as difficulties prioritizing and having other family responsibilities.
	Hard to say because when you're first diagnosed you may be overwhelmed
	...you are very emotional when you get diagnosed, and you've got a lot of questions...before you start surgery, that you have this opportunity to do this up front to understand what was going on
EM15 Taylor, Francesca et al. - 2016	Some pre-dialysis participants worried that if they took up formal peer support, it might give clinicians the impression they did not have the ability to manage their chosen therapy. T
EM17 DiGiacomo, M. et al. - 2015	"People who are stuck, like, they migrated 30 years ago and the cultures over there have changed, but they haven't. They're, sort of, stuck in that patriarchal, sort of, mindset." (PS)
EN01 Ekundayo, Olugbemiga T. et al. - 2012	ability to pay
EN06 Walters, Chasity Burrows - 2013	Medical errors were described by some as an issue of carelessness, and by others one of system design
EN06 Walters, Chasity Burrows - 2013	overwhelmingly regarded the acknowledgement of the potential for medical error erodes trust at a time when patients implicitly require it
EN06 Walters, Chasity Burrows - 2013	While patients relayed the accountability of medical errors across both HCPs and the healthcare system, few articulated any role for patients in their prevention.

<p>EN10 Brooks, Fiona - 2008</p>	<p>Dominant professional and organisational work place norms influenced how nurses responded to patient councillors' attempts to raise agendas</p> <p>The experiential knowledge of the councillors was predominantly viewed by the nursing staff as private experiences that were irrelevant to discussions of service</p> <p>o professional repositioning concerning the credibility of user experience</p> <p>contribution of personal situated and embodied knowl- edge to improved health care delivery,</p>
<p>EN15 Maten-Speksnijder, Ada J. et al. - 2016</p>	<p>Although the NPs took notice of the patients' experiences, they usually adjusted treatments based on their own examinations. Patients' experiences were subordinate to their own judgment a</p> <p>Information usually needed to be collected within 15–20 min- utes, including solving problems regarding wounds, diet and drug side effects; answering questions of patients and relatives and reporting all findings in the electronic patient record (EPR).</p>
<p>EN23 Davies, Freya et al. - 2014</p>	<p>it depends on having a positive feeling about the patient knowing what to use and how to use properly."</p> <p>"They do not have enough insight in the disease, they cannot judge the seriousness and then they yo-yo should I do it or wait a day. In short, the doubt."</p> <p>General Practitioner R7: "I do not trust patient in this way. I cannot prescribe it to everyone."</p> <p>Pulmonologist R9: "It requires different. . ."</p> <p>General Practitioner R7: "Familiarity."</p> <p>Pulmonologist R9: "Exactly, this requires not only familiarity, but a very good patient - physician relation</p> <p>e the consultation time for COPD cases is short</p>
<p>EN32 Hogden, Anne et al. - 2012</p>	<p>quality and timing of their decisions appeared compromised by a lack of motivation, and limited insight into their condition and the needs of their families</p> <p>Many patients were described as being "difficult" and having rigid personalities,</p> <p>identification of patients at risk of impaired decision-making skills was neither systematic nor standardized</p> <p>"They often don't have realistic expectations of how much help the medical profession can provide. They're wanting cure, but at the same time not necessarily seeing what they're going to be kept alive to be."</p> <p>Decisions regarding employment, artificial nutrition and hydration, home modifications and accommodation were reported to have considerable influence upon the carers' quality of life.</p> <p>Decision-making was disrupted if the patient and carer could not reach agreement, or when the patient's poor decision-making put the well-being of the carer at risk</p> <p>Some carers were reported to take a gate-keeping role that blocked access of the healthprofessional to the patient, and prevented patients from receiving services and information</p> <p>concern about the time lag between patients reporting symptoms and receiving a diagnosis of ALS access to health services was identified as a particular concern for patients who lived outside of the clinic catchment are</p> <p>"out of zone" patients were disadvantaged by long waiting lists</p> <p>restricting the funding of dedicated specialist ALS health professional positions; limiting clinic resources, such as production of evidence-based clinical guidelines; limiting patient numbers with access to specialist clinics; and curtailing health professional education and awareness of the specific needs of people with ALS</p>
<p>EN33 McDonald, Ruth et al. - 2008</p>	<p>dialogue and relationships described in terms of nurses giving patients information, rather than nurses and patients listening to each other's point-of-view.</p>
<p>EN34 Natale, Anthony P. - 2009</p>	<p>The waiting lists are getting longer everywhere and it's not getting any better.</p>
<p>EN39 Durme, Thérèse Van et al. - 2014</p>	<p>(Patients and informal caregivers' association, 2nd focus group) "If we hope that a patient decides for his/herself, we have to be sure that he/she understands the options. We should enable him/her to meet his/her peers, and we should provide information about support groups. This is not systematically offered by professionals."</p> <p>(Network coordinator, 2nd focus group) "We often see that medical doctors' priorities are different from patient priorities. T</p> <p>patients (a) miss information and therefore lack access to tools to make informed choices</p> <p>(Patient association, 1st focus group) "The informal caregiver is sometimes willing to coordinate. However, professionals take on this [coordinating] role, which seems logical, because it's part of their training. But this means that it is such a knot to undo, that it discourages families to ask for help from the coordination services.</p>
<p>EN40 Rise, Marit By et al. - 2013</p>	<p>solitary decisions made by either party as the opposite of involvement. T</p> <p>Service users expressed a general concern about being overruled by providers,</p> <p>Service providers expressed on the other hand concerns about whether patient and public involvement implied full service user governance and that the users were supposed to make all the decisions.</p>

	<p>resulting in poorer outcomes. Providers expressed a need for drawing limits to users making the decisions: There is a limit... where we have to avoid turning participation into... it cannot be weakness from the treatment team to not handle the situation. There is a crossing point where you no longer take responsibility for the patient. And if this is a patient who isn't capable to take care of himself, but chooses</p> <p>We were worried in the beginning... before we learnt differently... that these representatives should be persons who demanded things... their rights and needs... and wanted everything perfect on behalf of the patients. And that they wouldn't realize the practical problems with running a hospital, maintaining high medical quality, and that this is quite demanding. But we experienced that the public representatives [...] were clever, sensible persons who were able to see the political and economical reality...</p>
EN42 Fairbrother, Peter et al. - 2013	patients actively deferred responsibility for the medical management of their condition to healthcare professionals during periods of ill health

Table 25 - Low self-efficacy

CO01 Sacks, A. Abt et al. - 2016	I answered him that it was the same for me, and that whatever he considered best was fine
CO06 Graves, K. et al. - 2011	<p>it's in God's hands</p> <p>being less open to the technology</p> <p>less involved in healthcare</p> <p>including women's concerns over privacy and insurance discrimination, fear and uncertainty, and a lack of desire for the information.</p> <p>They express concern</p> <p>"don't want to know"</p> <p>familial influence may play a role African American women's disinterest</p> <p>sometimes it's really the family that doesn't want to know so they discourage</p> <p>hey just don't want to deal with it</p>
CO07 Alexander, Stewart C. et al. - 2012	Quantitative prognostic discussion about mortality without hedging was associated with lower patient education
CO08 Dowling, Joni E. - 2010	<p>many of these women did not recall their physicians discussing the topic with them, or encouraging the practice of yoga for stress management, or anything along that line.</p> <p>had counselors available to her but had no interest.</p> <p>nothing to do with cancer. She just wanted them to fix her</p>
CO09 Laws, M. Barton et al. - 2012	positive responses to physicians' confrontational and directive style were characteristic of the lower-educated groups.
CO10 Burrige, Letitia H. et al. - 2011	caregivers' consideration for the GP's lack of time might conceal their deeper aversions
CO11 Meyer, Samantha B. et al. - 2012	<p>10 years ago people just trusted in 'people with some sort of authority'</p> <p>lower SES participants F9 (aged 72), F13 (aged 72), F11 (aged 77), M10 (aged 76) and M11 (aged 75) are unquestioning of medical advice</p> <p>who's in a white coat could say anything to you and you'd trust them</p> <p>I don't think, query about it much. You know, so. So yes I suppose that is a matter of trust.</p> <p>participants' ages. Participants aged ≥70 were consistently more likely to trust, and less questioning of all medical professionals</p> <p>'I trust them</p> <p>You put your life in their hands</p> <p>know what they're doing—you don't.</p> <p>...of course I would put my, put my life into him as I did with the surgeon of course being, being the man with the brains he's obviously got and he knows exactly about the heart. He knows exactly what to do and what to say anyway.</p> <p>His myocardial infarction came as a shock to him and during the time of the interview, he said he was following whatever advice he was given without question</p> <p>more likely to trust in situations of risk</p> <p>M17 did not initially follow the advice of his physicians. However, his condition worsened significantly and became life-threatening. When asked if he questions his physician's medical advice now that he has had complications he responded: 'If they said 'jump' I'd say 'how high?'</p> <p>she still trusts the GP who made the error because 'okay you know your doctor's not God</p>
CO13 Venetis, Maria K. et al. - 2018	results suggest that the use of an impersonal tone coupled with increased details is associated with patient immediate post-visit reports of anxious preoccupation, intention to adhere, and satisfaction with the treatment plan
CO14 Hersch, Jolyn et al. - 2013	These women often preferred to trust recommendations from their doctor or the government: "It's confusing, especially if you're not mathematical, like me

	<p>I just want [my doctor] to say, 'You should go, you must go ... this is where you go.'</p> <p>All this hard work they've been doing for years, encouraging people to have mammograms ... now you are saying today, 'If you want to you can do it, but see it's your choice, see the percentages and you make your own decision.' ... Years and years saying, drumming in, 'You should have this every two years</p> <p>expressed concern that it would dissuade others from screening. In their view, this could lead to more breast cancer deaths and compromise the gains that screening had achieved for women's health</p>
CO17 Garon, M. - 2012	<p>Culture – I've recognized through the years that that's not everyone's culture (speaking up) and some people have been told not to speak up in growing up and they've learned other ways to get something done as effectively as speaking up</p>
CO20 MacDonald, Kath et al. - 2015	<p>the past I would've looked at the tests but now would err on side of listening to what they say and treat</p> <p>metimes you wonder, do they actually think I've got a social life, I've got a job, I've got a family and I've got a house and I've got all these other things happen</p> <p>Would tell them I didn't do anything</p>
CO22 Smith, Sian K. et al. - 2008	<p>t if you are making the decision, it leaves it open and most people would think, well no!</p>
CO26 Wray, Ricardo J. et al. - 2009	<p>professional recommendations to promote informed decision-making about screening rather than screening itself were not adhered to.</p>
CO32 Greenhalgh, Trisha et al. - 2010	<p>Contrary to expectations that Communicator would increase patients' autonomy, some seemed to use it as a means of becoming more dependent on their general practitioner, seeking instructions or affirmation when they might otherwise have made their own decision</p>
CO36 Wilkinson, Emma et al. - 2014	<p>I wish I could have a discussion or partnership but it is hard to speak to him</p>
CO37 Taylor, Elizabeth et al. - 2014	<p>goals were more likely to be therapist-led</p>
CO38 Duineveld, Laura A. M. et al. - 2016	<p>they assumed not everyone would be capable of taking responsibility of his/her own survivorship care, for example, among the elderly, immigrants or poorly educated people</p>
ED14 Vega, Gema et al. - 2014	<p>"I'm, I'm scared and me, it's, I always do what the doctor tells me. Me, yes, whatever they tell me to do, I do. If he tells me not to do something I don't do it, so."</p>
ED15 Goebbels, Adrienne F. G. et al. - 2012	<p>"When this moment of control is not there anymore, yes then it [motivation] is likely to abate. I really need a little bit of control</p> <p>it will always remain a weakness for me."</p>
ED16 Wright, Nicola - 2013	<p>how having a long-term condition led to them being and feeling devalued</p> <p>I have had two breakdowns so I know what it is like to be mentally ill and I know what it is like for your family to say you are nothing and you are worthless, you've let us down, you should be ashamed of yourself and all that</p>
ED6 Burda, Marika H. F. et al. - 2012	<p>These people don't read the instructions... If you don't understand, you should ask your doctor."</p>
EM07 Bhattacharya, Gauri - 2012	<p>A majority of the participants (75% of the women and 80% of the men) revealed their doubts about their ability to make the lifestyle changes prescribed by the guidelines they received after their T2D diagnosis.</p> <p>"Changes? Are you kidding? It is like learning how to live all over again."</p> <p>I hopeless, fearful of inevitable failure, and depressed.</p> <p>They felt nervous and helpless about what they perceived as the inevitable, final health outcomes felt very depressed because they did not know why they developed T2D when they followed God faithfully. However, they described their feeling of continued faith in "God to take care of them". Their feelings of helplessness may have further undermined their capacity to adhere to their T2D regimens.</p> <p>"I worry a lot about my diabetes and losing legs, and maybe earlier death. Doctor told me to prick myself three times a day to test blood sugar. But I believe in destiny. I left it to God. When He thinks it is my time to leave this world, I will be ready to go!"</p> <p>The majority of the women and men trusted that God is their healer. Who always takes care of them in their challenging life situations. This belief in destiny reduced their self-motivation to make changes by themselves. As a 55 year old man explained: "I have faith in the Lord, my wellbeing is in His hands. He saved me all the time. If you have faith in the Lord, the Lord will show you the way."</p>
EM11 Nota, Ingrid et al. - 2016	<p>"I never thought about that, but after having this conversation with you I am going to ask more questions." [Male, 66 years]</p> <p>"My involvement? Did I have a choice?" [Male, 44 years].</p>

	<p>Some patients had difficulties conceptualising patient involvement in MDM and gave somewhat ambiguous answer</p> <p>"I think highly of the medical profession. I trust them." [Male, 64 years].</p> <p>Patients who valued the expertise of the doctor mentioned that being well informed, being listened to and having their problems taken seriously were important prerequisites for satisfaction with this form of decision-making: "She decides, but I insist that she takes it... takes me seriously." [Female, 61 years].</p> <p>Immediately rejects the patient's questions or suggestion</p> <p>Doctor does not provide adequate information Gives too little information "He is very good at his job, but I have to ask him everything, for example when I don't agree with something he says. I really need to drag it out of him." [Female, 74 years]</p> <p>Patient is not aware of alternatives or possibility to choose</p> <p>"But it [an alternative] has to be out there somewhere and the doctor needs to tell me." Did you ask for an alternative? "No, I did not. And I did not know I could, either. If the doctor says it's effective, then I think: You know best." [Female, 69 years]</p> <p>Patient lacks knowledge "Of course many decisions are made for you, because you yourself cannot... I did not know anything about this when it all started." [Female, 17 years]</p> <p>Patient lacks assertiveness</p> <p>Does not dare to speak up to the doctor "I feel I do what the doctor says very quickly. No nagging, just do as he/she tells you. That is nonsense, I know that. You should keep on asking for clarification until you are satisfied." [Female, 45 years]</p> <p>Is reserved in asking questions or does not know which questions to ask</p> <p>I believe we are partly to blame for that, too, because we do not keep on asking. And then, at home, you have all those questions. You think about them, but actually you should just immediately ask the doctor any questions you might have." [Male, 66 years]</p> <p>Patient does not yet accept diagnosis "I want to be involved, but [...] it takes so much effort to deal with [the diagnosis], so I really wanted to hide it all the time." [Female, 57 years]</p>
EM13 Kowitt, Sarah D. et al. - 2015	<p>. Similarly, in North Carolina, PSs frequently mentioned that it was not their position to tell a peer what they should or should not be doing; instead, they viewed their role as assisting peers in setting mutually decided goals.</p>
EM17 DiGiacomo, M. et al. - 2015	<p>For example, although women may be perceived as more proactive, older generations may feel that the 'doctor knows best' and accept his or her word without question. Depending on the doctor-patient rapport and individual characteristics and skills, women may not feel confident to ask questions during consultation</p>
EM17 DiGiacomo, M. et al. - 2015	<p>"Women used to come in and tell us things, a lot of things, you know, about their local doctors and how they didn't listen to them, that's a major one. And how they just pushed them off as long as they got them out of the place in five minutes...they would write a script, especially with women with menopause, they were the main complainants...male doctors didn't want to know about it, basically</p>
EN01 Ekundayo, Olugbemiga T. et al. - 2012	<p>fear of discovery, u</p> <p>inertia, apathy</p> <p>unemployment</p> <p>lack of insurance coverage for care.</p> <p>ack of self efficacy</p> <p>lack of self esteem</p> <p>lack</p> <p>of trust of the health system</p> <p>fear of knowing prostate cancer status,</p> <p>lack of knowledge;</p> <p>technology barriers</p> <p>Don't know</p> <p>unaware</p> <p>They make excuses,</p> <p>Fear might stop them</p> <p>The fear of having prostate cancer, • Fear of going to doctor and finding it out.</p> <p>Fear of personal discovery</p>
EN02 Browne, Annette J. et al. - 2012	<p>You're trying to reflect on, you know, check my attitude: was I being condescending? And I'm sure many times I am, because you know, like, you slip into that role right? You're the doctor</p> <p>You have to look at the privileges that you gained as a consequence [of your professional status</p>
EN05 Graffigna, Guendalina et al. - 2014	<p>ignoring controls or by avoiding direct contact with the specialist</p> <p>I would like to have a remote control, a kind of telemedicine tool to feel controlled and supported</p>

EN06 Walters, Chasity Burrows - 2013	<p>common sense implies if the hospital tells you to do it, you do it I choose not to know every little detail, not to be as involved</p> <p>He described feeling rushed, as though his nurse did not actually expect him to have any questions, noting her movement toward the door</p>
EN10 Brooks, Fiona - 2008	<p>leave if they feel that their agendas are being subordinated to organisational or political agendas</p>
EN11 de Wit M, Abma T et al. - 2013	<p>s felt ignored, frustrated or unable to contribute.</p> <p>Feeling like an observer</p> <p>Feeling not prepared for the job</p> <ul style="list-style-type: none"> ▶ Feeling too shy to relate personal stories ▶ Assumption that experiences are obvious <p>Feeling unable to contribute</p> <ul style="list-style-type: none"> ▶ Hierarchy of professions ▶ Power imbalance
EN15 Maten-Speksnijder, Ada J. et al. - 2016	<p>Barriers by patients' reluctance to talk and acute problem</p> <p>The strategy 'connecting with patients' was also undermined when patients, for different reasons, were reluctant to talk about their experiences.</p>
EN21 Buck, Deborah et al. - 2014	<p>'; contributors' lack of confidence about contributing at meetings). confident enough to make your point)</p> <p>find it difficult to "say something which might imply a criticism of their clinician"</p> <p>You've got trialists in the [meeting] who are trained to run clinical trials. And then you've got one lay representative who may be slightly intimidated by everyone else, who'll not be able to truly give their views, may be slightly overawed. (CI 14)</p>
EN23 Davies, Freya et al. - 2014	<p>: "the patient should not determine the indications for these drugs, only physician. That is, if some exacerbation occurs, it is natural to examine the patient, and only then recommend the prescription"</p> <p>, it's not that everyone feels like taking actions independently. Many will prefer talking to their doctors or rather their lung doctors or to be hospitalized some patients seemed to prefer seeing a doctor when their symptoms deteriorated and would not be happy starting medication themselves</p>
EN28 Safo, Stella et al. - 2016	<p>these are doctors and researchers, they've got far more education than I do</p> <p>They don't feel confident. They don't feel that they are up to it. They don't feel that they have anything of value to offer.</p> <p>s the] fear of the unknown, fear of their own skillsets as agencies, fear of the ivory tower"</p>
EN35 Gien, Lan et al. - 2017	<p>they were confused and lacked the confidence in handling their body's reactions to DM</p> <p>"It's so hard to keep your blood sugar at a certain reasonable limits. It's really trial and error and it's really difficult"</p>
EN36 CLOCHESY, JOHN M. et al. - 2015	<p>I can understand them running behind or whatever, but you know it seems to me like somebody should come into the waiting room and say 'You know we're running behind.' Nobody says anything. That blows my mind</p> <p>If I was laying on the street bleeding to death, I would die before I would go to that hospital and let them touch me.</p>

Table 26 - My time, my life is not so important

CO10 Burrige, Letitia H. et al. - 2011	<p>caregivers may see no genuine reason to engage with their GP. For example, it may simply not seem important enough, as "the majority... don't think to ask their GP</p> <p>caregivers may consciously dismiss themselves as patients: caregivers' propensity to trivialise their own health "wasting [the GP's] time</p>
CO11 Meyer, Samantha B. et al. - 2012	<p>I think with our generation, because we were brought up respecting doctors, teachers and policeman</p> <p>I don't think, query about it much. You know, so. So yes I suppose that is a matter of trust.</p>
ED9 Santos-Livengood, Christie A. - 2015	<p>In my culture, going to the doctor is not something – you go to a doctor if you absolutely need to go to the doctor, like if you're dying, you have to go to the doctor</p>
EM11 Nota, Ingrid et al. - 2016	<p>Patient lacks assertiveness Does not dare to speak up to the doctor "I feel I do what the doctor says very quickly. No nagging, just do as he/she tells you. That is nonsense, I know that. You should keep on asking for clarification until you are satisfied." [Female, 45 years]</p>
EM17 DiGiacomo, M. et al. - 2015	<p>"...older women treat doctors like little gods up to a point</p>
EN06 Walters, Chasity Burrows - 2013	<p>taking HCPs' time unnecessarily. concern about being a burden it's just the way I feel, like feeling uncomfortable with ringing the bell</p>

	when patients do not ask questions "it may be true that they don't have any, but it might also be that we just don't have the energy to bother.
EN21 Buck, Deborah et al. - 2014	confident enough to make your point)
EN36 CLOCHESY, JOHN M. et al. - 2015	they felt that their time was not as important as the provider
EN39 Durme, Thérèse Van et al. - 2014	They are afraid to express themselves, afraid to be ill-perceived and cumbersome."
EN42 Fairbrother, Peter et al. - 2013	Many patients expressed reticence in initiating contact with healthcare professionals. They felt that they should not 'bother' their GP and indicated that they would delay consulting until they considered that they had become sufficiently ill to justify an appointment.

Table 27 -Distrust, fear of institutions,fear of being labelled

CO06 Graves, K. et al. - 2011	medical mistrust fear of being labeled medical mistrust as a cultural factor in the underutilization of genetic counseling and testing in African American women historically well known for [experiencing] atrocities African American patients oftentimes tend to be more suspicious about [genetic testing]... it's another way of [labeling them]. privacy and insurance discrimination
CO11 Meyer, Samantha B. et al. - 2012	he trusts his GP he replied: 'I got to learn to trust him' whether or not he trusts a healthcare professional is dependent on the medical problem: more likely to trust in situations of risk
CO14 Hersch, Jolyn et al. - 2013	some wondered whether our presentation might be part of a government plan to reduce spending on breast screening, using overdiagnosis as justification I think what they're trying to do here is cut out breast screening ... or cut out the funding. .
CO15 Hart, Ruth I. et al. - 2017	barriers affected if and how concerns were shared, and could be reinforced by clinicians' reactions to disclosures of fatigue.
CO19 Brez, Sharon et al. - 2009	patient "distrust" or lack of confidence in the family physician's judgment about diabetes management, they don't want to hear it from us
CO20 MacDonald, Kath et al. - 2015	do wonder if any of us are getting the truth about how much drug is taken, it's true we don't trust them, should we trust them? No There were patients staring at the floor, no eye contact, patients not saying anything at all during difficult transition clinics. So that's the extreme end of the lack of partnership. they suggested that some patients were expert in navigating and manipulating systems to get what they wanted:
CO26 Wray, Ricardo J. et al. - 2009	distrust
CO27 Dolce, Maria C. - 2011	Disenchantment, a profound emotional experience characterized by sadness, disappointment, dissatisfaction, hopelessness, frustration, anger, and distrust I do like reading about what is out there and wish doctors kept up with it, too. Totally disenchanting with my doc, as you can tell. I cannot put into words how sad we were when we found out we had not had the most up-to-date treatment frustrates the patient who is searching for answers and good treatment
CO35 Goddu, Anna P. et al. - 2015	It's a lot of us that we don't [go to the doctor]. When I was watching the video, I thought about myself and how when I go into the doctor's office, I don't always tell her exactly what's going on with me and how I feel.'
ED16 Wright, Nicola - 2013	All of us are paranoid about Doctors and Medics and the point of things like the EPP is that it can do things for you or help you to do things that Doctors can't.
EM07 Bhattacharya, Gauri - 2012	skeptical of the medical care system. They were suspicious of medical recommendations about regularly taking medication. "My doctor told me to take pills regularly. Doctors always say that! I can take care of myself. If I do not feel good, I'll take pills. (53 year old woman).
EM08 NANTON, V. et al. - 2011	Though not in general averse to seeking medical help, men described initial reluctance to consult the general practitioner (GP) with regard to their urinary symptoms. not recognising or being willing to recognise the potential seriousness of symptoms. Reluctance on the part of African-Caribbean men in general, was explained in terms of fear of cancer, which was seen as inevitably resulting in death, or fear of loss of sexual function. Fear o

	information was important (if you get the information it helps you to cope) only the three youngest had actively questioned their doctors, though several had sought information from books and the media.
EM09 Grande, Stuart W. et al. - 2013	Participant 5, whose experiences were legitimated by others interviewed, talked about how negative interactions with law enforcement reinforced his sense of vulnerability and suspicion of the world around him.
EM11 Nota, Ingrid et al. - 2016	Patient holds back information "Sometimes I take less, but he does not know. And I do not feel any different." [Male, 66 years] "I did not tell the rheumatologist, because... they do not acknowledge alternative medicine." [Male, 50 years]
EM16 Vries, D. H. de et al. - 2016	Participants also mentioned experiences with rejection within health institutions, dentist practices, and even when trying to obtain a mortgage for purchasing a house. One out of five respondents who did disclose felt that they have been discriminated against or excluded became more reserved due to stigma" (R 283). What is interesting with this last participant is the fact that he or she attributed her nondisclosure to HIV-related stigma. the largest gains can be made by disclosing to employers, colleagues, and children in the household. Also notable is the number of discriminating responses within the health professionals (32%). This is less for women, yet more among Dutch or Western respondents (relative to minorities). Heterosexuals experience more discrimination from civil servants and social workers than other groups.
EM17 DiGiacomo, M. et al. - 2015	doctors attributing presentations to mental health issues, concerns over labeling and stigma, generational and cultural communication and socialization norms, Anglo-dominated world views and language, education level, time restrictions and comorbidities, and misconceptions of English language mastery. Moderator: Are women viewed more negatively if they're a 'frequent flyer'? PS: ...I'm just thinking if that was a man that had been asking for a podiatrist? Yeah. I do think they - they put women into the 'nut' category, yeah. She was told she was a hypochondriac and I don't think she is. I think she's just concerned with her health. She's a very smart lady. I just think she challenges this particular GP, and he doesn't like it. So, I think that's what's going on there. So we're trying to find her another GP who doesn't mind being challenged. But, this is a lady who will stand up for herself. She's won, but it's taken her months."(PS) I think the biggest problem that I have come across with severe pain is the actual patient being believed... My mother-in-law suffered for 40 years and she's still not being believed...I think, to be believed is one of the biggest problems... women's perception of being dismissed by doctors who perhaps do not appraise their complaints as requiring investigation. a source of women's disempowerment was the dominance of men in health professional positions I'm used to trying to get what I want out of the medical system. And I will pursue my goals and get them to fit in with me and do what I want and give me a referral to someone if I want it." (CM) This leads cynicism and loss of trust within the workforce, as well as in consumers
EN01 Ekundayo, Olugbemiga T. et al. - 2012	disrespectful treatment in the healthcare system,
EN05 Graffigna, Guendalina et al. - 2014	ignoring controls or by avoiding direct contact with the specialist he doctor-patient relationship sometimes appears challenging and patients tend to avoid contact "Honestly I hate the controls: my doctor is usually in a hurry, and I don't feel like asking for more details. I feel stupid to ask." "Sometimes I ignore the appointments and I don't go." I do not think he would understand. H
EN06 Walters, Chasity Burrows - 2013	I feel very confident in this particular hospital, but in some other location I would be worried
EN09 Flournoy, Minnjuan W. - 2011	Patients, especially, discussed being uncomfortable with several dentists knowing about their HIV status.
EN14 Hirjaba, Marina et al. - 2015	Discouraging and accusing the patient was perceived to have a significant negative impact on their morale and led them to ignore their duties and decrease their commitment to self-care.
EN18 Mitchell-Brown, Fay et al. - 2017	Mistrust of providers is a barrier to access of health care in the Hmong community
EN19 Garcia, Jonathan et al. - 2015	fear and mistrust characterized men's relation to social and public institution the environment of hostility and danger that BMSM faced created mistrust, and social isolation

	a “culture of mistrust” in communities, such as Harlem, where some participants expressed feeling that a police presence was there to “protect the White people gentrifying the hood.”
EN24 Powell, Rhea E. et al. - 2016	Finally, participants spent extensive time discussing patient intimidation and general mistrust of the health system, as well as personal fears related to seeking and receiving diagnoses (Table 4). Participants explained that many patients felt intimidated by doctors and the health system, and that patients often believed that primary care providers were not motivated to understand their life situations, due to lack of time and lack of interest. patients did not form trusting relationships with their providers, thus they hesitated to ask questions, had limited follow-through with recommendations, and felt more comfortable seeking care in the emergency department. seems like it has been passed on from maybe generations to generations the distrust of a doctor and saying, well, if I go to the doctor he is going to find – if I go for one thing, he’s going to find another thing or I can take care of myself and I don’t need to go to a doctor
EN36 CLOCHESY, JOHN M. et al. - 2015	Once trust was breached, it was almost impossible for the provider or system to earn it back.

ANNEX 4: Empowered individuals, empowered communities - Codes and quotations

Table 28 - Autonomy

CO01 Sacks, A. Abt et al. - 2016	patients are perfectly able to make decisions for ourselves and that we need to do it each patient's point of view is different I also like to have a lot of information
CO02 Dellasega, Cheryl et al. - 2011	the MI intervention encouraged them to be responsible for their own care. In this way, they disclosed more openly and also took ownership of the lifestyle changes they needed to make in order to be healthy. empowered with informatio discipline to sit down, discuss things, g
CO04 Delea, Sarah et al. - 2015	he importance of social support
CO07 Alexander, Stewart C. et al. - 2012	(‘that is a condition we can manage for many, many years with these drugs’)
CO08 Dowling, Joni E. - 2010	I attempted to be an advocate for my own care I did my research on the clinical trials that he was suggestin socially and publicly became an activist 's husband also became an activist in the fight against breast cancer starting her own non-profit believed lymphedema did not have enough visibility
CO09 Laws, M. Barton et al. - 2012	taking their medications was intrinsi- cally satisfying: R: What I like to do, I like to go dancing, right, and then I like to take my meds on a regular basis. Yet another had decided to stop altogether for some time, until her T-cells are depleted, with her doctor's knowledge but disapproval.
CO11 Meyer, Samantha B. et al. - 2012	When asked if he trusts his GP he replied: 'I got to learn to trust him' and that his trust developed over time rather than being blind. higher SES participants in secondary prevention were unanimously found to be reflexive with regard to medical decisions and trust in medical professionals she has reservations about trusting all physicians so she specifically chose to see a physician she trusts.
CO13 Venetis, Maria K. et al. - 2018	impersonal language in discussions of the patient's treatment options may allow the patient to focus more objectively on her options and thus leave her feeling more empowered
CO14 Hersch, Jolyn et al. - 2013	I think the terms 'overtreatment' and 'overdiagnosis' are negative, they're loaded terms, and I don't think it's a necessarily negative occurrence women speculated about ulterior motives behind overdiagnosis research Women valued screening as an opportunity to gain a sense of reassurance that everything was all right knowledge might also give such women more of a sense of control the amount of information women required before screening would vary according to personal preferences conserving energy; managing demands by planning ahead; taking breaks for rest and recovery; and looking after themselves better
CO15 Hart, Ruth I. et al. - 2017	recognizing that it's part of the condition It validated interviewees' experiences and concerns the booklet had affected, or would affect, their approach to managing fatigue, and reported making, or planning to make, small but potentially significant adjustments to their behaviour. making more time for sleep, taking more exercise and attending more closely to diet.
CO19 Brez, Sharon et al. - 2009	independently adjusting medications (especially insulin) knowing how to "deal with sick days" "non-compliance" was used by participants in all of the focus groups to describe situations when patients did not behave as expected by the PCPs
CO20 MacDonald, Kath et al. - 2015	heavy emphasis by HCPs on adherence with physiotherapy and medicines, but YP appeared to be very comfortable disclosing nonadherence to treatment Expert patient as navigator (self, systems, processes) Normalcy (minimisation, embeddedness of treatment burden)
CO23 Davies, Jane et al. - 2014	enthusiastic about spreading this knowledge Now I research the medications before I take them together Many patients had experience using technology to detect potential medication interactions

<p>CO31 Zulman, Donna M. et al. - 2015</p>	<p>I went home and went on the computer and I went searching all the medications and then looked at the other stuff I had been taking for other issues, you know is there any potential interaction</p> <p>patients with MCCs often feel that they must serve as their own expert and advocate for their needs.</p> <p>reverse the conventional knowledge balance of patients and physicians: BYou have to be your own advocate</p> <p>research everything you can</p> <p>this research was something done independently of interacting with medical professionals</p> <p>technology empowered them in their role as advocate</p> <p>...tried to arm myself with enough information with the technology, with the right care providers so that I control the disease; the disease doesn't control me</p> <p>patients described a need for online resources that would connect them with patients who had similar MCC profiles and support their roles as experts and advocates. T</p>
<p>CO33 Vilhauer, Ruvanee P. - 2014</p>	<p>flexibility may have given women a greater sense of control</p>
<p>CO35 Goddu, Anna P. et al. - 2015</p>	<p>the desire to engage in personal storytelling reflected a sense of personal responsibility to help each other</p> <p>increased their skill and confidence at handling common situations.</p> <p>opportunity to practice skills and share feedback</p>
<p>ED14 Vega, Gema et al. - 2014</p>	<p>The male component considered professionalism of caregivers, accurate and detailed information about care options, diagnostic tests and treatments, and the skills and status of the professionals treating them as positive</p>
<p>ED14 Vega, Gema et al. - 2014</p>	<p>A female profile would demand health care services closely related to a holistic approach to the health problem, wherein the person is more important than the disease, and positive and satisfactory relations would be those in which there is an emotional bond.</p>
<p>ED16 Wright, Nicola - 2013</p>	<p>That's one of the main things giving people the tools to empower themselves, we've all got a condition and we are all going to be in control of it</p>
<p>ED7 Hurt, Tera R. et al. - 2015</p>	<p>Men, we have to be willing to accept the help.</p>
<p>ED8 Sekse, Ragnhild Johanne Tveit et al. - 2014</p>	<p>By gaining more knowledge about their own situation, such as the possible bodily changes and impacts on everyday life, the women understood themselves and their bodily changes better.</p>
<p>ED9 Santos-Livengood, Christie A. - 2015</p>	<p>Family teaching tended to frame sex and sexuality in the context of puberty, reproduction or love between two people. One participant shared: "My mom was always very open about sexuality. And so I had information since I was little about how babies were born and where they came from and how they were made. And so there was a lot of information when it came to that about safe sex practices, like using condoms or contraceptives but definitely abstinence."</p>
<p>EM05 Oliffe, John L. et al. - 2008</p>	<p>Survivorship was a strongly represented idea</p> <p>"Winning the War on Prostate Cancer," had a strong military theme that permeated the meeting through the use of "battle" metaphors, along with various props (dog tags, World War II metal helmets, and disarmed grenades). Militarism was introduced early on in the conference when the host introduced himself as the general and made a call for "reinforcements in the battle against prostate cancer." Dog tags were then issued to the conference delegates to signify their soldier status and preempt deployment in locating the cause (enemy) and administering the cure (entering into combat to defeat the enemy), in the ultimate war against prostate cancer.</p>
<p>EM06 Phillips, Janice et al. - 2011</p>	<p>I've been given a new lease on life and each day is an adventure and I take it very serious. ... What am I going to do today? What kind of fun are we going to have? And I just make it happen</p> <p>Life itself has taken on a different meaning, you know. I always tell people to give me a sweat-shirt that says, 'whatever.' I don't sweat small stuff anymore, and I was one that, I was like always stressed. I wanted to be in control of everything. I wanted to get this done; caring about everyone else, and now it's about, it's okay, and me.</p> <p>Participants expressed concern that providers thought they were too young to have breast cancer. Even for those seeking care for abnormal breast findings, their concerns were not always met with appropriate attention. One participant commented on the watchful waiting recommended for young women with breast symptoms. She noted: She [physician] told me, 'you're a healthy thirty-four year old, see you in five years'... I got on the elevator, went upstairs—at the time I was working in surgery</p> <p>—so I talked to one of our head nurses and I'm like, 'you know, that don't sound right because I think—I know my primary doctor is not going to do a needle aspiration—so I would feel better if I went to at least one of the breast surgeons. Do you have someone that you recommend?' And so, that's how that happened. So I called down to breast, and got setup to see Dr. and met with him</p> <p>He was not a good doctor to me..... He pulled out the freaking algorithm and showed a flow chart like, 'Oh, since you have this, then we will do this.' And I'm like, 'you're going to boil my life down to a flowchart?' So it didn't make me feel like he was really interested in my recovery; so I didn't go to him. So I went and got my second opinion from another lady</p> <p>I think more women—definitely younger, black women—need to pay attention to their bodies. They need to know their bodies; know what's changing and not be afraid to say, 'hey, something doesn't feel right.' Because like I say, especially working in the cancer unit, we are getting younger women. They will come in at 18 and 19, 20 and once they come in, it's too late. We are going to make them comfortable. We're going to try what we can, but the cancer</p>

	<p>is rampant and that's because you choose—your body told you something was wrong and you choose to ignore it. And I would just like women, especially the younger women not ignore.</p> <p>I tried to live on a philosophy that God only puts on you what you can handle</p> <p>However I would say God. I would just say the Holy Spirit.... it just came to me that, 'you know what, that is not your journey</p> <p>My spiritual life has taken on a new meaning, you know. I definitely know that it was through my faith that I was brought through this. So everything that I can do to give glory to just give glory to God for that, I do. I remember being first diagnosed, I was like, "okay, God, I don't know what you're trying to get me to see. What is the message in this? But I always say, if you are going to use me in any kind of way, then I'm willing to do that. Breast-cancer education and awareness has become my passion</p>
EM08 NANTON, V. et al. - 2011	<p>. All but two described themselves as having been healthy fit young men (I could move a mountain) at the time they arrived in the UK.</p> <p>Traditional remedies had played a central part in the family armamentarium. Men described bitter tasting bush and herbal teas (black tea, black mint, jack in the bush, fever grass, cerasee) that were prepared by their mothers, to be taken both as preventative and curative measures. All except the youngest two men continued to use these, The two youngest men had less knowledge and little memory of these remedies. Though they also sought dietary ways of augmenting their medical treatment, these consisted of products they had become aware of more recently. . . . they say pumpkin seeds are good for you, so I started to buy some</p> <p>From it they drew strength, helping them live with difficulties associated with their cancer, other forms of morbidity and other aspects of their lives such as wid- owerhood or family problems.</p> <p>A number of men were involved with local community groups and some, who were still physically more active, had established informal support networks with other local men with prostate cancer. T</p> <p>I am happy, you know? I don't let things get me down. I don't let things get too far beyond my reach. I have no complaints is what I am saying. (Mr P</p>
EM09 Grande, Stuart W. et al. - 2013	<p>"it makes me think about those who didn't have what I have . . . make sure that I can contribute as my other brothers did."</p> <p>the value of their own personal strength as a kind of indicator or measuring stick against which they see themselves.</p> <p>"once I began to have my self-pride and my own cultural pride in myself than therefore these little instances they are meaningless to me because I have my own cultural pride. I have my own racial identity within myself."</p> <p>strong African-American men impact me. It just gives me a vision, you know what I'm saying, about what I want to accomplish. The goals that I want to reach." A sense of needing to "be better"</p>
EM10 Peterson, Jennifer L. et al. - 2012	<p>t being a "buddy" can lead to mutually supportive interactions. In the context of HIV, buddies assigned to provide those newly diagnosed with support have also been found to experience social acceptance as well as personal growth and empowerment</p> <p>"The rheumatologist made that decision." But shortly after, she showed to have (obviously) influenced the decision and decision-making process: "And he was very much aware of the fact that I did not want prednisolone." [Female, 41 years].</p> <p>I get side effects, then I believe I should be the one to decide whether or not to continue taking the medication, because I feel my body best</p> <p>"I am in control over my own body. If there is a decision at stake, I decide by myself. I do not need anybody else to help me." [Female, 74 years].</p>
EM11 Nota, Ingrid et al. - 2016	<p>expertise of the doctor highly but wanted to be a part of the decision-making process because they themselves feel their symptoms best, wanted to have some level of control or wanted to critically evaluate the impact the doctor's advice would have on their personal situation and discuss this</p> <p>"I want to share in the decision-making process. As a patient, you should follow the doctor's advice, you should not say it is nonsense, you cannot do that, but I do critically evaluate his advice. [...]"</p> <p>It is about you, you are responsible for your own body, but because you do not have the knowledge, you also depend on the doctor, so he needs to be responsible as well. So you share the decision-making." [Male, 50 years]</p> <p>"Starting [medication]. Because the medication can be quite intense, it is very important to me to think about it: Do I want this? A</p> <p>Last year I was in so much pain. My knees were killing me. I called the doctor and like a drug addict I begged for an injection. Normally I wait until the next check-up and the blood level results, but now I took control." [Female, 54 years]</p> <p>Patient lacks assertiveness</p>
EM12 Wiljer, David et al. - 2013	<p>"I felt, emotionally, that I was stronger and that I have a lot of sources that I can go and follow. I can finish this journey."</p> <p>"I felt very empowered actually."</p> <p>"...it could be helpful to you and it could make you feel in charge of what you have to do."</p> <p>"I just find that everything was so helpful and relaxed. I felt so relaxed. I didn't feel like a typical, sort of, doctor's appointment. It felt like at this point, there was hope."</p> <p>"...the opportunities in the community for helping different areas...really good to know that they're out there...I feel like it's important to know that they're there...a lot of patients do want to use those support systems."</p>

	Participants reported the SC helped them become more in charge of managing their own care by providing them with the resources, information and the organizational skills that they thought necessary to help them through their cancer journey. Participants reported feeling more empowered and hopeful.
EM13 Kowitz, Sarah D. et al. - 2015	Providing information was also a way of reinforcing peer empowerment; gaining trust to establish relationships with peers, particularly in the beginning of peer contact; and alleviating people's anxieties, fears, and stressors
	Respondents wanted vicarious encouragement that improvements were possible, and a role model, not someone imbued with pity.
	Not because the medics are bad or anything, it's just because they've just not walked that journey in the same way. They've sort of walked along-side you and are more observing, whereas this is more living it. (Patient 7)
EM15 Taylor, Francesca et al. - 2016	A number of participants, in particular patients dialysing at home for several months, and their carers, intimated they would be more comfortable being the provider rather than the recipient of support; the role of helper was both more familiar and more attractive
	Projected to me is you are a needy person and I don't like that picture of myself. (Carer 7)
	Having choice and control in relation to certain aspects of the timing and delivery of formal peer support were important considerations for some interviewees.
	greater choice, control and ownership
	disclosure as the liberation from a secret they no longer have to carry with them.
	After disclosing, some participants felt freed because they could be themselves again. This feeling of being oneself was related to the fact that HIV was part of their identity: "I want to be myself and HIV is part of that" (R 119).
EM16 Vries, D. H. de et al. - 2016	"Through divergent reactions of others about my HIV, I have experienced personal growth. I became a lot stronger through this" (R 128). Disclosing even helped some participants in personally accepting their HIV-positive status
	"by disclosing my HIV-positive status to others, I came to accept myself" (R 64)
	"by being open about my HIV more often, I have become stronger and more confident about myself" (R 70).
	[I don't disclose because] I am not HIV"
	. They believe that when stigma is reduced they will be able to disclose their HIV-positive status to other people more easily, which will also make it easier for them to effectively self-manage their illness.
	people will see what a person with HIV really looks like. One participant illustrated this point by saying "I disclose] for educational motives . . . to show people we are not sick, we are not dying, and we are not contagious" (R 100). One participant, for instance, said that disclosing is the only way to "break the silence of HIV" (R 267). Another participant said that disclosure is a way to "fight prejudices" (R 335)
	I'm used to trying to get what I want out of the medical system. And I will pursue my goals and get them to fit in with me and do what I want and give me a referral to someone if I want it." (CM)
	Women may adapt to changed capacity for physical function or symptom experiences rather than constantly attending to them and labeling them as illnesses
EM17 DiGiacomo, M. et al. - 2015	Ensuring understanding and facilitating communication are essential to women's empowerment, as explained by one participant:
	"Women really need to be empowered, and we all know that people feel comfortable in their first language, especially when they're older, because people regress to their culture
	other women on the phone, or at the shopping centre... It's this verbal, and I think if you cut that off, you're not giving women the tool that they use."
EM19 Bess, Kimberly D. et al. - 2009	Tension 3: Surplus Powerlessness versus Collective Efficacy
	This tension relates to pervasive powerlessness, particularly in Healthy City, that characterized staff members' relationship to their own agency in effecting change in their organization and in the community
EN03 Locock, Louise et al. - 2011	Empowerment and involvement in managing one's health
	Enriching personal life, e.g., learning new things, meeting new people, social interaction
EN03 Locock, Louise et al. - 2011	These were people who were specialising in that subject...It tended to be they gave you much more time ... They took, say, nine or ten readings, which gave them a much more accurate reading of your blood pressure.
	Whereas your GP would only have time for one ...I mean it's so relaxed. Y
EN06 Walters, Chasity Burrows - 2013	participants described their awareness as intuitive, such as navigating the environment to avoid trips and falls.
EN11 de Wit M, Abma T et al. - 2013	feel confident enough to say something
EN14 Hirjaba, Marina et al. - 2015	It would not be good if I was totally under the control of others and couldn't influence my own life and disease care.

EN16 Holmberg, Christine et al. - 2015	The feelings of security and empowerment that the women voiced and their sense of changing their fate were also related to trial participation overall
EN20 Pinto, Rogério M. - 2009	sense of commitment more assertive, more empowerment as a result of the collaboration.
EN37 McCabe, Catherine et al. - 2014	patient motivation, coping ability/response, optimism or positivity, overcoming guilt, and confidence in self-management I just sit back and relax, no good getting annoyed about it, just take it, sit back and read the paper, turn on my wireless and listen to a bit of music, you know. (JO) I would love to go back to work, I would love the purposefulness of it and the freedom of being able to earn your own money.
EN41 Thompson, Jill et al. - 2014	to contact with a greater range of technical and scientific information, which appeared to provide her with a greater sense of agency ability to cope with the disease renegotiate aspects of their self and identity along more positive or constructive lines

Table 29 - Feelings and diagnosis

CO06 Graves, K. et al. - 2011	it's in God's hands African American women might fear being labeled as having a genetic mutation information about risk can be reassuring
CO08 Dowling, Joni E. - 2010	horrible, shocked, fearful, scared, terrified, stunned, or numb convinced herself it was not cancer a surreal moment She would have preferred initially hearing the diagnosis face-to-face so that her husband could hear what the doctor was saying was at work and saw two voice mail messages within two hours, telling her to call her doctor had cancer as a teenager, so learning over the phone or face-to-face did not matter to her. It was weird to find out over the phone, but later I appreciated being in my own space. Being able to decide what I wanted to do, rather than being in the doctor's office. As a clinician, I knew this was probably not a good sign . I wasn't extremely happy to hear about it over the phone there's no good way to hear psychological distress of prognosis and fear of recurrence separation from their social attachments radically changing her assumptions cancer could come back dealing with their body image, such as loss of hair, eyebrows, and eyelashes; scarring; and changes in body hormones their self-esteem and self-worth improved by the experience I always had low self-esteem...so I don't know if it has affected it anymore Even not having reconstruction, my body image is not worse I probably have better self-esteem than I did prior to all of this I still don't feel beautiful ancer treatment centers to better communicate the initial diagnosis of breast cancer
CO09 Laws, M. Barton et al. - 2012	Most long-term survivors had gone through an initial period, lasting from months to years, of nonadherence, on-and-off adherence, or nonengagement in care, often but not always associated with active substance abuse negative feelings, including anger or betrayal initial stage of denial or avoidance was common was drinking heavy, real heavy I wouldn't take no medicine and then I'd break down a slow suicide." That's what I'm doing, I guess, because I stopped taking my medicine when I was using. I was dibbing and dabbing decisions to start taking care of themselves and to live in religious terms I asked the Lord to bless me and take care o by the grace of God that's why I'm here today I went through acceptance, reinforced my love for Jesus So God let me come up
CO13 Venetis, Maria K. et al. - 2018	Control variables of pre-visit anxious preoccupation, patient education, and patient marital status were entered in the first block, Adjusted R2 = .70, F(3, 47) = 39.49, p < .001. Pre-visit

	<p>anxious preoccupation positively ($\beta = .81, t = 10.27, p < .001$) and education negatively ($\beta = -.17, t = -2.18, p = .03$) predicted post-visit anxious preoccupation.</p>
CO14 Hersch, Jolyn et al. - 2013	<p>psychological and physical consequences of experiencing a cancer diagnosis and enduring treatment unnecessarily: "It could cause a lot of unnecessary stress</p> <p>disagreed with the notion that it could be considered a bad outcome to find a cancer and have treatment that was ultimately not needed. These women perceived "overdetection" as a value laden term</p> <p>I think screening is ... something you go through to have a peace of mind. But as to ... after that, if you are diagnosed, then you have to weigh and look at the various options that you hav</p> <p>Rather than seeing treatment as the immediate logical consequence of a diagnosis, they would want to consider "watchful waiting" or alternative therapies</p>
CO15 Hart, Ruth I. et al. - 2017	<p>Fatigue disrupted activities and increased their physical and/or mental demands. Motivation to engage in social or leisure activities was undermined:</p> <p>get put on hold, because you're tired</p> <p>people did not understand their fatigue, or connect it with their condition</p> <p>they attributed it to age, apathy or other – undiagnosed – illnesses</p>
CO26 Wray, Ricardo J. et al. - 2009	<p>knowledge there is about prostate cancer treatment invokes fear and discomfort</p> <p>Men fear that they will always be labeled as being sick after the surgery</p>
CO32 Greenhalgh, Trisha et al. - 2010	<p>Many participants' information and communication needs were not primarily for codified data (for example, blood glucose levels) but for practical knowledge of how to live with their condition and for emotional support.</p>
CO33 Vilhauer, Ruvanee P. - 2014	<p>the illness, and treatment regimens and side effects, can leave women feeling that they have little control over their lives.</p> <p>when I was first diagnosed, this was, I had so much to absorb of this that I wasn't sleeping well and everything. And with online support, there's chances that you could find somebody at 2 and 3 in the morning that you can talk to."</p> <p>I felt that every- body was focused on the disease. And how horrible it was to have metastatic cancer, and how terrible the doctors and the medical system was, and all of that</p> <p>I would leave the group feeling worse than when I arrived</p> <p>there was insufficient emotional content in her CMSG</p> <p>the focus of her CMSG had been limited to cancer</p> <p>group's reluctance to discuss death and dying</p> <p>CMSGs, unlike FTFGs, allowed them to receive support without being overwhelmed by exposure to the prospect of debilitation and dying.</p> <p>And people breathing through tubes in their throat, and just looking very sick. And I think you could talk to people on an e-mail basis and not have that, I mean, it's not that I didn't have sympathy for them, but, you know, it's frightening when you see people you think, oh no, am I going to be like that? That's not the way I want to go. I mean, to begin with I had thoughts of suicide</p> <p>women can participate in a CMSG and still not engage in some discussions, and so it may offer a less threatening alternative to a FTFG</p> <p>might be compelled to face realities they are not ready to face. Mae (aged 59) said that she had felt hesitant about discussing death and dying in her FTFG.</p> <p>this topic was avoided for the most part in all three of the CMSGs in this study, even though many other anxieties and fears were often discussed</p> <p>we really never got into deep, serious conversations about our dying</p> <p>Talking about dying provokes fear both in the speaker and the listener</p> <p>Fear ... It would have been the same, regardless [of whether it was an on-line or face-to-face group].</p> <p>the absence of body language cues exacerbated the difficulty of communicating in CMSGs about an issue as sensitive as the possibility of imminent death.</p> <p>Silence is interpreted differently in a CMSG than in a FTFG, particularly in this population. It can mean that someone has become very ill or possibly died.</p>
ED14 Vega, Gema et al. - 2014	<p>some people had a more positive stance, to the point where some considered their cardiovascular event as an opportunity to improve</p> <p>Thank goodness I got the stroke. I got this renewed urge to, to take on the world. I think that whoever doesn't learn from it to, hmm, it's such an intense life process, to live in another way, right</p> <p>reason for depression or as misfortune</p> <p>Such an unfortunate disease; it just makes you wanna cry. I feel powerless and so down I could just die.</p> <p>But me, I, for me it's the opposite. It's that I'm all topsy-turvy. S'all backwards. I'm fuming, furious, I'm against all what's happened to me.</p> <p>You just say, "Right, well, that's it." When you can, you can, and when you can't, well just put up with it.</p>

	<p>I'm scared</p> <p>I was forty-seven and I was in the prime of my life, in my opinion. But from then on it's like I've only got half my life. It broke me</p> <p>They make me feel like I'm not a person, right, not useful anymore. There's heaps of things I wanted to do, and now I don't</p> <p>Me, my normal life, yes. Me, right now with the heart issue, it's that now I don't consider myself as being sick. I know I had a heart attack. I overcame it and I've really got my life back, and I think I've made it normal, practically as I had it; as I had it before.</p> <p>social status, educational level, and socio-economic level (represented as economic, social, or family responsibility), all of which also affected how patients faced the disease and its consequences</p> <p>Employed patients with economic or family responsibilities experienced their disease much differently than retired patients or homemakers with other kinds of responsibilities.</p> <p>I'm over it. It's that right now, right now my heart isn't a problem for me anymore.</p>
ED5 Albarran, Cynthia R. et al. - 2014	<p>depression, bereavement or shock surrounding a recent health scare</p>
ED7 Hurt, Tera R. et al. - 2015	<p>, "It's like, I cannot protect my family now. I cannot provide for my family."</p> <p>resigned himself to accepting his t2dm diagnosis as just something that occurs with time if you live long enough. "At some point in your life, you're gonna get got."</p>
ED8 Sekse, Ragnhild Johanne Tveit et al. - 2014	<p>though the people around them claimed to understand what the women were going through, they would not believe it to be possible</p> <p>Having been diagnosed with cancer was an existential, shattering experience that evoked aspects of life and death. I've thought about cancer every day, ten times a day, a hundred times a day... (...)... I've been through death many times... but I was relieved of these thoughts when I joined this group.</p> <p>the existential 'marks' remained with them and that they lived with an alertness to recurrence or new cancer.</p> <p>It's a hell of a disease, because you never really know if you are cured</p> <p>Berit struggled with major bodily changes following chemotherapy.</p> <p>She experienced severe bodily limitations</p>
EM04 Boise, Linda et al. - 2013	<p>One person told a story about a friend whose doctor commented that he seemed depressed. The man took this remark to be offensive and then became angry; the doctor then became concerned the man might have some kind of psychosis.</p>
EM06 Phillips, Janice et al. - 2011	<p>I've been given a new lease on life and each day is an adventure and I take it very serious. ... What am I going to do today? What kind of fun are we going to have? And I just make it happen</p> <p>Life itself has taken on a different meaning, you know. I always tell people to give me a sweat-shirt that says, 'whatever.' I don't sweat small stuff anymore, and I was one that, I was like always stressed. I wanted to be in control of everything. I wanted to get this done; caring about everyone else, and now it's about, it's okay, and me.</p> <p>A newly diagnosed unmarried woman described marriage and child bearing as being central to her quality of life. She envisioned one day getting married: I am very excited about marriage. I cannot wait to finally meet the man that wants to marry me; very, very excited—can't wait to have children. My mom is like beyond excited for that</p> <p>He was not a good doctor to me..... He pulled out the freaking algorithm and showed a flow chart like, 'Oh, since you have this, then we will do this.' And I'm like, 'you're going to boil my life down to a flowchart?' So it didn't make me feel like he was really interested in my recovery; so I didn't go to him. So I went and got my second opinion from another lady</p> <p>My spiritual life has taken on a new meaning, you know. I definitely know that it was through my faith that I was brought through this. So everything that I can do to give glory to just give glory to God for that, I do. I remember being first diagnosed, I was like, "okay, God, I don't know what you're trying to get me to see. What is the message in this? But I always say, if you are going to use me in any kind of way, then I'm willing to do that. Breast-cancer education and awareness has become my passion</p>
EM07 Bhattacharya, Gauri - 2012	<p>I hopeless, fearful of inevitable failure, and depressed.</p> <p>immediate reaction that they would have the status of sick persons for the rest of their lives.</p> <p>participants worried about "taking pills/meds everyday", "keep it [blood sugar] under control", "constant watch, cannot eat like before", "careful of diabetes attacks [too low or high blood glucose]"</p> <p>They felt nervous and helpless about what they perceived as the inevitable, final health outcomes. They had witnessed people in the community with "loss of legs" (lower limb amputations) and more often "blind[ness]." Both female and male participants were distrustful about disclosing their T2D status to their peers. "It is a rural community, word will spread, and all will look at me with sympathy,"</p> <p>"I worry a lot about my diabetes and losing legs, and maybe earlier death. Doctor told me to prick myself three times a day to test blood sugar. But I believe in destiny. I left it to God. When He thinks it is my time to leave this world, I will be ready to go!"</p>

EM08 NANTON, V. et al. - 2011	<p>not recognising or being willing to recognise the potential seriousness of symptoms. Reluctance on the part of African-Caribbean men in general, was explained in terms of fear of cancer, which was seen as inevitably resulting in death, or fear of loss of sexual function. Fear o</p> <p>The only thing about this sickness which get me was the way the doctor just say 'You've got cancer'. You know he didn't come with any diplomatic way of saying it</p> <p>Only two of the men described extreme distress upon receiving the diagnosis. As well as fearing death, these men were concerned that their cancer may be contagious. In contrast, others described receiving their diagnosis calmly. Participants explained their response in terms of religious faith</p> <p>You see as I always call on the Lord and all of these things I said 'Lord Jesus help me to go through this thing' and then I go through it and I came home. (Mr L)</p> <p>continence problems</p> <p>difficulties with sexual function</p> <p>Well it's there. I can't do nothing to it. Why worry because it'll only make it bad for you. I mean you can't do anything for sickness so it don't make sense to worry too much.</p>
EM10 Peterson, Jennifer L. et al. - 2012	<p>. Listen to their fears and in many ways relive my own experience, which at times is kind of hard. O</p>
EM11 Nota, Ingrid et al. - 2016	<p>Patient does not yet accept diagnosis "I want to be involved, but [...] it takes so much effort to deal with [the diagnosis], so I really wanted to hide it all the time." [Female, 57 years]</p>
EM12 Wiljer, David et al. - 2013	<p>Hard to say because when you're first diagnosed you may be overwhelmed. Everything is so quick because they want to treat it as quickly as possible, so it's hard to schedule..."</p> <p>"I don't know what would be the right time...you are very emotional when you get diagnosed, and you've got a lot of questions...before you start surgery, that you have this opportunity to do this up front to understand what was going on. But you don't know how emotional you will be throughout this whole process..."</p> <p>"...close to the beginning of the journey...that's when there are a lot of questions about what's it going to be like to live on chemo, what's it going to be like to go through radiation, how tired am I going to be, do I have to quit work, do I need help with my children..."</p> <p>"In the beginning I had a lot of attention, I had the oncology nurse, the doctors, everybody, appointments, appointments.. constant attention...now at the end of my treatment I'm not getting that attention so this came at a great time for me."</p> <p>several participants experienced substantial stress concerning their inability to return to work or ability to deal with new problems that resulted from their reduced employment and income. This was expressed to the clinician and participants reported the SC helped them find information and advice regarding how to properly manage their current situation.</p>
EM15 Taylor, Francesca et al. - 2016	<p>established kidney failure engenders an altered conception of self in relation to others; patients and carers mentioned having to adjust their lives and lifestyle and how this changed relationships with family members, friends and work colleagues</p> <p>o self-esteem. Respondents expressed concern about being perceived as overly 'needy' or lacking social resources</p>
EM16 Vries, D. H. de et al. - 2016	<p>Self-stigma was also quite apparent in the qualitative reactions of participants. One participant, for instance, said, "[Due to my HIV] I have the feeling that I am worthless" (R 253). Another participant said, "I became more reserved due to stigma" (R 283). What is interesting with this last participant is the fact that he or she attributed her nondisclosure to HIV-related stigma.</p> <p>Selective disclosure was mentioned by 60% of the participants, maing it one of the most common self-management strategies.</p> <p>disclosure as the liberation from a secret they no longer have to carry with them.</p> <p>By having no secrets, nobody can accuse me of anything later on in life</p> <p>After disclosing, some participants felt freed because they could be themselves again. This feeling of being oneself was related to the fact that HIV was part of their identity: "I want to be my- self and HIV is part of that" (R 119).</p> <p>Disclosure is dependent on the person or group [I encounter]" (R 172). Another respondent said "I don't disclose in contexts where I don't know the people" (R 443)</p> <p>It is particularly striking how disclosure is an activity for peers, spouses, and medical professionals, as opposed to the workplace. More than half of the participants cite the fear of stigmatizing attitudes of others if they disclose as a reason for such selective disclosure</p> <p>"I don't disclose because of the stigma that gets stuck to you if you do" (R 271); "I don't disclose out of fear that people will reject me or will give an odd reaction" (R 161); or "I think that disclosure is synonymous to social exclusion and therefore infinite loneliness" (R 255)</p> <p>I don't disclose be- cause] I am not HIV"</p>
EN01 Ekundayo, Olugbemiga T. et al. - 2012	<p>fear of discovery</p> <p>Fear of personal discovery</p>

EN02 Browne, Annette J. et al. - 2012	the impact of not “approaching me too fast”
EN04 Cook, Catherine - 2012	I was too devastated to think that [the diagnosis] was correct,’ process of self-discovery, to put HPV in context
EN05 Graffigna, Guendalina et al. - 2014	The reliance on drugs is a constant reminder of the patient’s illness stat lack of adherence to treatment is often a sign of the patient’s reluctance to accept the awareness of his/her pathological status. the doctor as the “executioner” who communicated the diagnosis, and thus dramatically changed the patient’s life all patients reported feelings of anxiety and anger and described their disease as “dirty” and “binding” [My diabetes] is like a tax collector, pushy, arrogant, always present...i it makes me feel like a “slave”, slave of insulin pens, of finger pricks, loss of freedom a condition from which patients occasionally try to escape My diabetes is like my conscience who punishes me when I make a mistake , I engage in traditional dancing, because it allows me to forget my disease describe themselves using words such as “ill person” and “diabetic”. high psychological impact of diabetes on individual identity and self- imag to make patients feel more like patients, rather than persons you are forced to think of “IT” blocked can’t accept deny frozen totally unequipped in term of know- ledge and information about their disease and the strategy to manage i These patients often feel alone in the face of the enormity of their disease, and they fail to completely accept their diagnosis, thus resulting in emotional barriers and other difficulties in truly engaging in their own health management. “It is difficult to accept being The main need for this patients is to answer to the question “Who am I?” The others just treat you as a patient, you are not a person anymore.” strongly isolating.
EN06 Walters, Chasity Burrows - 2013	I just think it’s so vulnerable, when you come in here
EN09 Flournoy, Minnjuan W. - 2011	To be honest, I can’t tell the difference between this being for people who are HIV-positive or negativ
EN14 Hirjaba, Marina et al. - 2015	being honest regarding own condition
EN15 Maten-Speksnijder, Ada J. et al. - 2016	NPs rarely addressed the emotional aspect of the situation: NP tells them that the blood results are not good and the young woman says, ‘just as I expected, I am so tired’. The NP says that she regrets that the serum creatinine level has risen. Then, events rapidly accelerate. The NP callsthe physician in for a consultation, and he tells the patient a percutaneous nephrostomy is needed to save the kidney transplant. The husband remains silent; his wife asks for some explanations. After the physician has left the room, the NP informs the patient how she can manage the catheter at home. The NP has to arrange the hospital admission, and she asks the couple to wait in the full waiting room. The NP works quickly because she is already running 20 minutes late. Eventually she informs the couple in the waiting room where they are expected to go patients’ stressful life circumstances as well as the complex problems NPs may have to handle. Femke’s mother opined that Femke resisted her body failure, which affected her activities, while Femke struggled with her identity as a person with a chronic conditio
EN16 Holmberg, Christine et al. - 2015	had felt vulnerable to developing breast cancer before they were approached about STAR, experiencing it as a danger to their health. Some of the interviewed women had a longstanding relationship with breast cancer You know, I knew I was very high risk because of the family thing, but never until I was diagnosed all hell broke loose and the diagnosis was given. In my family, on my mother’s side, my mother’s mother passed away with breast cancer at age 56 Understanding disease as genetic reshaped familial relationships in the US (Finkler 2000). A mother’s breast cancer was no longer only a concern for the mother’s well-being but directly influenced her daughter’s health status as well, shifting the latter’s categorisation from healthy to being at risk for developing breast cancer described how they had lived with relatives who did not openly discuss their affliction or the debilitating effects it had on them

	<p>he didn't really talk about it and she never let me see her scar. I never saw her scar until the day she died</p> <p>frightening</p> <p>worrisome</p> <p>The interviewees' narratives echo the master narratives of silence and isolation that surrounded breast cancer in the past, which is contrasted with openness and proactiveness in the present</p>
EN18 Mitchell-Brown, Fay et al. - 2017	<p>living with diabetes is stressful</p> <p>expressed difficulty in living with the disease that has no cure</p> <p>you will have to live with it until the day you die</p> <p>those medicines are what you will have to take for the rest of your life</p>
EN24 Powell, Rhea E. et al. - 2016	<p>personal fears related to seeking and receiving diagnoses</p> <p>fear of receiving a serious diagnosis prompts patients to delay care. "Fear</p> <p>I think it's fear. Fear causes people not to interact because you're afraid of what you might hear. A</p> <p>But because of fear you don't ask something</p>
EN29 Richardson, Lorilei M. et al. - 2016	<p>understanding that a condition was chronic and would require such work for the rest of their lives weighed heavily</p> <p>"It's all consuming. It's every meal you eat. Everything you pick up to eat. Then you got the pills to take, all the different pills to take each day, and checking your blood sugars. It's quite consuming"</p>
EN32 Hogden, Anne et al. - 2012	<p>Respondents identified limited clinical understanding of ALS as an impediment to acceptance of the diagnosis by both patients and their families</p> <p>limited public awareness of ALS as a disease entity was seen to create delays in patients seeking a diagnosis.</p> <p>shock patients experienced on receiving a terminal prognosis for an unfamiliar condition with family's ability to take in information, and to plan for future care needs (</p> <p>patients who struggled to accept their condition responded passively to physical deterioration, seeking assistance only when their condition had become unmanageable.</p> <p>people were very reluctant to make big decisions, not quite believing that this was the case, or not quite believing that things were going to progress</p> <p>It feels like a mixture of hope and disbelief, with disbelief, I think, overwhelming the hope.</p> <p>"It is very challenging when they don't accept the diagnosis, because if they don't do that, they don't accept any interventions. And there comes a point where it's too late to institute various intervention</p> <p>You try and talk to them about that and they're not ready to hear it. They're not ready to, they don't want to talk about the long term</p> <p>It's about trying to be responsive to them when they are ready to hear,</p> <p>Crisis theory is 'respond at the time, do what you can, calm it down, normalize it, be ready for the next crisis</p>
EN33 McDonald, Ruth et al. - 2008	<p>panic or shock</p> <p>impacted adversely on their ability to take in information and exercise independent judgment</p> <p>I say a newly diagnosed diabetic you feel responsible, because there is an awful lot of information to take in, people are often shocked by it</p> <p>They get a bit of a shock that they're diagnosed with something</p> <p>"I don't want to die young, I want, I'm only young and I want to do this, this and this"</p>
EN35 Gien, Lan et al. - 2017	<p>, most felt confused, vulnerable, and</p> <p>unsure whether their own information and advice from others were accurate.</p>
EN37 McCabe, Catherine et al. - 2014	<p>"In the beginning you would just have got it from a consultant or the doctor—probably looked up the net after that.</p> <p>You do feel isolated, when your first given, told the news I mean I just wouldn't accept it at all ... and that just led to depression, just couldn't cope</p> <p>"feeling fed up,</p> <p>worthless</p> <p>thinking of euthanasia,"</p> <p>disappointed</p> <p>having a lack of motivation," and little "joyfulness.</p> <p>when breathing was good participants were optimistic, calm, and positive. If breathing was poor participants reported being conscious of the condition,</p> <p>5 major areas of concern in relation to social activities; these include ability to drive, employment, hobbies, financial issues, and travel. O</p> <p>Some nights I go and I might not get up and dance at all ... if they are fast there's no way I could do them. But even if I do not do a dance I'm still keeping in touch with the friends that I made at the dancing over the years.</p>
EN41 Thompson, Jill et al. - 2014	<p>prematurely ended (or postponed) their career as a direct result of their experience of cancer. This marked a significant loss for many participants and was often referred to in terms of loss of structures of relevance in their daily lives.</p> <p>I wasn't really expected to survive from and, touch wood, I am still surviving, but it's obviously made me look very differently at life. And I was getting older, and after having six months off . . . I started to go back part time and I started to build up my workload. And it just became evident, really, that it wasn't working .</p>

EN42 Fairbrother, Peter et al. - 2013	I think some people will never accept the fact that they have a chronic lung disease that will never get better. . . therefore there is no motivation to self-manage. . .
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Table 30 – Responsibility

CO02 Dellasega, Cheryl et al. - 2011	make their own decisions and set realistic goals ‘Taking responsibility for it [diabetes]. . .I find it very beneficial and very supportive. It isn’t that you get any revelations of things you don’t do, but it just keeps you on track.’ d I do know it’s my responsibility I get little help at home
CO04 Delea, Sarah et al. - 2015	they admitted that they chose not to follow doctors’ instructions and many took responsibility for the worsening of their condition
CO09 Laws, M. Barton et al. - 2012	All said they would disclose nonadherence to their current providers. any participants said they did not necessarily disclose in the past when they had not committed to treatment. Some were adherent in spite of difficulties, because they believed it was necessary to pre-serve life and health In spite of their good current relationships and trust for their providers, not all respondents said they always follow the provider’s recommendations do not take their ARVs when they drink alcohol, takes days or weekends off to give his body “a break” , you know to help yourself accountable for taking your medicine, taking it on time.
CO11 Meyer, Samantha B. et al. - 2012	The differences between higher and lower SES primary prevention patients may also be explained by participants’ ages
CO31 Zulman, Donna M. et al. - 2015	feel that they alone fully aware of their constellation of symptoms and self-management needs For me having the mix of diseases, I have been walking around in a bubble thinking I’m the only one in the world that has got this.
CO35 Goddu, Anna P. et al. - 2015	promoting tangible behavior change
CO37 Taylor, Elizabeth et al. - 2014	to empower and educate individuals and impart the concept of rehabilitation. T
ED14 Vega, Gema et al. - 2014	The male component considered professionalism of caregivers, accurate and detailed information about care options, diagnostic tests and treatments, and the skills and status of the professionals treating them as positive
ED16 Wright, Nicola - 2013	acceptance of their long-term condition, both by themselves and other people they needed to acknowledge the limitations it imposed on their lives but for it not to be the defining factor of who they are: you are the only person who can manage that.
ED7 Hurt, Tera R. et al. - 2015	“It affects you being the head of your family. Your family looks to you The overarching framework for the program should be one of empowerment and recognition that there are consequences for choices individuals make regarding their health (Men, we have to be willing to accept the help.
EM02 Miller, Robin Lin et al. - 2012	You know, in life we have to learn that there are deadlines that we have to meet. Whether it’s in school, whether it’s at work, whether it’s, finances such as, you know
EM05 Oliffe, John L. et al. - 2008	Many men also wore pins and wrist bands to signify their prostate cancer survivor status
EM06 Phillips, Janice et al. - 2011	I guess because I’m getting older now the majority of women in my family developed breast cancer around middle age or whatever, like early 50’s and 40’s like that- my grandmother and my great grandmother. It’s just, I feel that I should be more concerned about it now, As much as men understand, he doesn’t really think about it. I have to remind him of certain things like, ‘this is my bad arm, don’t touch me on that arm, I don’t like to be touched back there,’ just stuff like and, and reminding, you know, that he ‘you need to know certain things like, I had my ovaries out. So in case I can’t speak for myself, medically, you need to know what’s going on To have my husband go with me to all the appointments; and there is something to be said about when you’re the patient, you are so distracted and scattered brain—as a medical student, you hear all this, that they don’t hear half of what you say—and u leave and you’re like, ‘they didn’t tell me that?’ ‘Yes, we did,’ you just didn’t, couldn’t hear. So to have someone else who was there with me to ask questions that I would have ask if I were in my right mind,
EM07 Bhattacharya, Gauri - 2012	A majority of the participants—14 (88%) of the women and 13 (87%) of the men—acknowledged their individual responsibility to take care of their T2D diagnosis. How- ever, they also revealed their

	perceived helplessness over controlling their diabetes and their fatalistic attitudes about diabetes-related health consequences "I worry a lot about my diabetes and losing legs, and maybe earlier death. Doctor told me to prick myself three times a day to test blood sugar. But I believe in destiny. I left it to God. When He thinks it is my time to leave this world, I will be ready to go!" The majority of the women and men trusted that God is their healer. Who always takes care of them in their challenging life situations. This belief in destiny reduced their self-motivation to make changes by themselves. As a 55 year old man explained: "I have faith in the Lord, my wellbeing is in His hands. He saved me all the time. If you have faith in the Lord, the Lord will show you the way."
EM08 NANTON, V. et al. - 2011	if there is a problem they can come and ask me. You know I don't know everything but I've got through a lot since day one – six years now . . . people can just ask. (Mr P) I am happy, you know? I don't let things get me down. I don't let things get too far beyond my reach. I have no complaints is what I am saying. (Mr P)
EM11 Nota, Ingrid et al. - 2016	It is about you, you are responsible for your own body, but because you do not have the knowledge, you also depend on the doctor, so he needs to be responsible as well. So you share the decision-making." [Male, 50 years] Although they did prefer SDM, they wanted the doctor to be responsible for the outcome of the treatment. "He is the expert and, in the end, it's his responsibility. He is the one who is truly responsible, but we decide together." [Fe- male, 54 years].
EM16 Vries, D. H. de et al. - 2016	an effect of nondisclosure due to (the fear of) stigmatizing attitudes seems to be that PLWHA become less adherent to their medication because they, for instance, do not want to take their medicines in front of other people. O Selective disclosure can bring one's self-esteem back and empower people as a way to gain social support and be freed from a secret. Yet, stigma influences disclosure negatively as experiences with or the fear of stigma motivates a nondisclosure, both selective or completely. Both forms of nondisclosure create relative silence about respondents' HIV-positive status, which allows the high HIV-related public and structural stigma within the Dutch society to remain existent.
EN06 Walters, Chasity Burrows - 2013	When examined in isolation, safety was described simply as the prevention of harm using common sense. I I don't think patients should have to do anything to be safe Well it's common sense to be cautious.

Table 31 – Guilt

CO02 Dellasega, Cheryl et al. - 2011	Patients felt that in contrast to standard care where they received negative feedback (guilt provoking, nagging, shaming) from both family and health care providers in an attempt to coerce them into taking responsibility for their diabetes, the MI intervention encouraged them to be responsible for their own care. In this way, they disclosed more openly and also took ownership of the lifestyle changes they needed to make in order to be healthy
CO04 Delea, Sarah et al. - 2015	competing psychological demands
CO06 Graves, K. et al. - 2011	Providers reported psychological impact, false reassurance and guilt as some of the negative effects of testing If a sister doesn't have the gene and her sister does, then the sister that doesn't have it might feel guilty.—Breast Surgeon
CO08 Dowling, Joni E. - 2010	felt guilty over her illness and for a long time felt like a bad mother I feel guilty, like I must've done something to have gotten this." She also felt guilty over having to depend on her husband for her care. felt guilty for having breast cancer. Although YWWBC7 saw no change in her self-esteem and self-worth, she experienced moments of guilt. She stated, "I feel guilty, like I must've done something to have gotten this." She also felt guilty over having to depend on her husband for her care. She said, "When I was getting married, my vision of what my first year of marriage would be like was very different
CO15 Hart, Ruth I. et al. - 2017	This lack of understanding left them feeling guilty and anxious about their work, domestic and social lives: You feel like you're lazy, you know. I sort of come in and I'm thinking, you know, "Eeh, I'm such a lazy so-and-so". [Interviewee C] Some days, I handle it really badly... I won't pace myself, some days I, I still, just approach things badly, or just won't talk to people t validated interviewees' experiences and concerns, and some- what alleviated the guilt associated with decreased activity: 'Makes you feel a bit more like you're not making it up. [Interviewee F] I think [people] around me are thinking 'you can't keep talking about this - now you have to get on with your life.'

ED8 Sekse, Ragnhild Johanne Tveit et al. - 2014	even though the doctor said it might take time... but when you don't have a name for it... you feel a bit lazy...
ED9 Santos-Livengood, Christie A. - 2015	They described the cultural value of "traditional" marriage and heterosexual reproduction and child rearing, and their subsequent feelings of inadequacy, disinterest or resentment to meet those expectations.
EM06 Phillips, Janice et al. - 2011	I think he just feels bad because he lost my mom to breast cancer and I think maybe his having to watch me suffer through it—it made him angry with me.. He's done and said things that have been very hurtful. He says things like I use cancer to get what I want or I think that because I have cancer, like nobody can tell me "no" about anything. It's been a really emotional rollercoaster. I have not—dated and stuff....because I know that I can't give the emotional support I guess that most people want.
EM07 Bhattacharya, Gauri - 2012	Indeed, they expressed the guilty feeling that they would violate church sanctity if they discussed their own T2D with other church members. A felt very depressed because they did not know why they developed T2D when they followed God faithfully. However, they described their feeling of continued faith in "God to take care of them". Their feelings of helplessness may have further undermined their capacity to adhere to their T2D regimens.
EM11 Nota, Ingrid et al. - 2016	Patient lacks assertiveness Does not dare to speak up to the doctor "I feel I do what the doctor says very quickly. No nagging, just do as he/she tells you. That is nonsense, I know that. You should keep on asking for clarification until you are satisfied." [Female, 45 years]
EM15 Taylor, Francesca et al. - 2016	self-esteem. perceived as overly 'needy' lacking social resources Projected to me is you are a needy person and I don't like that picture of myself. (Carer 7)
EM17 DiGiacomo, M. et al. - 2015	For example, al- though women may be perceived as more proactive, older generations may feel that the 'doctor knows best' and accept his or her word without question. Depending on the doctor-patient rapport and individual characteristics and skills, women may not feel confident to ask questions during consultation
EN02 Browne, Annette J. et al. - 2012	The whole thing of addiction is having people listen and not judging. And most doctors, I know, except for the select few that are here, they are all judging
EN05 Graffigna, Guendalina et al. - 2014	My diabetes is like my conscience who punishes me when I make a mistake
EN33 McDonald, Ruth et al. - 2008	. They provide a justification for situations in which patient outcomes are not optimal. If such circumstances threaten nurses' identities, then a refusal to accept culpability helps defend against such threats. It's their choice to be non-compliant ... I empower them with that privilege of saying "yes" or "no". If they're continually non-compliant and you've gone through all the nice approaches ... you've got to go to the bottom line which I don't, no one likes doing but sometimes you have to use those, not threatening that's not the word ... shock tactics (
EN36 CLOCHESY, JOHN M. et al. - 2015	It's difficult for me one with explaining things and I apologize,
EN37 McCabe, Catherine et al. - 2014	participants almost exclusively felt guilt for their diagnosis and development of the condition. The foundation of this guilt was linked to regrets about previous behaviors such as smoking, perception that the cause was self-inflicted. I felt guilt and feel slightly that my condition is my own fault. And I have a huge guilt trip about that psychological feeling that they were restricting others' enjoyment. patients who do not seek adequate support due to a "guilt complex" may have their recovery stifled and experience decreased quality of li
EN42 Fairbrother, Peter et al. - 2013	Many patients expressed reticence in initiating contact with healthcare professionals. They felt that they should not 'bother' their GP and indicated that they would delay consulting until they considered that they had become sufficiently ill to justify an appointment.

Table 32 - Empowerment facilitators

CO08 Dowling, Joni E. - 2010	employer and co-workers as part of their support system need for patient care advocates
CO26 Wray, Ricardo J. et al. - 2009	the need for multi-faceted initiatives that include health institutions working in partnership with media and community organizations, worksites, schools and churches the need to mobilize community leaders, survivors and family members (including females in men's lives) to expand community participation, provide interpersonal support, heighten

	knowledge about screening, increase community discussion about prostate cancer, and diminish cancer fear
ED16 Wright, Nicola - 2013	they needed to move away from the medical model, towards a social view of health and wellbeing
ED8 Sekse, Ragnhild Johanne Tveit et al. - 2014	'To be with others who have been through the same thing, has been a tremendous support safe boundaries of the community,
ED9 Santos-Livengood, Christie A. - 2015	the importance and lasting impact of family-based sex education. One participant identified that the information she received from her family protected her from internalizing shame-based education "I feel that my queer identity – I think – well, I think it's related to kind of queer culture and the queer community which I feel is probably a little more informed and a little more active than the heterosexual culture. I don't know if that's a gross generalization, but that's how I feel.
EM02 Miller, Robin Lin et al. - 2012	The image and role young men are encouraged to adopt is of young men with integrity who are defined by educational and professional aspirations and who behave accordingly
EM04 Boise, Linda et al. - 2013	In our Mahber, there are 6 families. Two of us belong to this Mahber, as we were friends in Ethiopia and I came to Portland because of my friend. We contribute money every month so that we have a group saving in Mahber. This money can be used when something bad happens to one of us
EM05 Oliffe, John L. et al. - 2008	Many of the groups prided themselves on the way they functioned and recognized their contributions to local as well as global populations of prostate cancer survivors in many ways. Many men also wore pins and wrist bands to signify their prostate cancer survivor status. For example, reef knot pins (designed by the Vancouver Island Prostate Cancer Research Foundation in 2002), symbolizing strength, unity, and courage, became the national symbol of PCSGs, and blue prostate cancer wristbands with the same motto were commonplace at the meetings activism He stressed the need for patients to lobby government, policy makers, and regulatory organizations to accelerate the Food and Drug Administration (FDA) approval of emergent pharmacologically based prostate cancer treatments. The second speaker, a urologist, suggested "nihilist doctors," who did not truly care about their patients, were unacceptable. A third speaker drew on her expertise in securing monies for charities to outline how PCSGs might successfully lobby media to increase government funding for prostate cancer research.
EM08 NANTON, V. et al. - 2011	local community groups a
EM09 Grande, Stuart W. et al. - 2013	brotherhood participant 14 who said, about his relationships with other African-American men, I learn from them. First and foremost it was a bad outcome, but we're still on going with that relationship. I had a couple good ones and a couple bad ones "once I began to have my self-pride and my own cultural pride in myself than therefore these little instances they are meaningless to me because I have my own cultural pride. I have my own racial identity within myself." African American men learned individual skills to navigate relationships and the hardships of life through storytelling, older generations, and small groups if you don't know your descendants are kings then you're not a king. respect and trust for older generations and what they have overcome through resiliency. He said, well my uncles and my fathers, both of them have mentored pretty good.. . What seemed to connect these men to each other and their past was much more valuable than what divided them. Despite this competition, there was a need to stay connected to other African American men. Participant 16 talked about fitting in with other men, "it's just that I feel like I gotta be around them, because I got such a good bond with them." Participant 14 thought about his responsibility to other African American men, "this goes back to the teachings of Elijah Muhammad. If you see someone with a dirty glass offer them a clean one. And see which one they drink from. You did your part. That's it."
EM10 Peterson, Jennifer L. et al. - 2012	Some of them [social network peers] provide me with a very positive outlook. The support they give me, the hugs, the handshakes, those types of things. When you go through that mental, emotional crisis, I have some peers that come through for me. I can't find the words for it. They come through and pull me out of that rut that I find myself in.... They pull me through and, vice versa, I do the same. With my friends (with HIV), they understand the disease and that I get tired very quickly. When we do activities, they kind of watch for when I'm starting to show fatigue and they either say, "Well

	<p>let's sit down and rest," or they'll say, "Well, why don't we call it off, the rest of the thing off, and do something else later?"</p> <p>network support by allowing socializing and bonding, instrumental support through monitoring the participant's well-being, and esteem support by providing an atmosphere of acceptance and self-worth.</p>
EM13 Kowitz, Sarah D. et al. - 2015	<p>"People weren't looking for emotional support. I think it just came into play. Sometimes people may not know exactly what they need but once they are a part of something, they get to see." Over time, PSs in all projects reported coming to provide substantial emotional support after developing relationships with peers.</p> <p>Providing information was also a way of reinforcing peer empowerment; gaining trust to establish relationships with peers, particularly in the beginning of peer contact; and alleviating people's anxieties, fears, and stressors</p>
EM15 Taylor, Francesca et al. - 2016	<p>informal peer support experience, involving patients and carers conversing with others in the same situation as themselves, generally as a result of incidental encounters at Renal Units.</p> <p>Not because the medics are bad or anything, it's just because they've just not walked that journey in the same way. They've sort of walked alongside you and are more observing, whereas this is more living it. (Patient 7)</p>
EM16 Vries, D. H. de et al. - 2016	<p>After disclosing, some participants felt freed because they could be themselves again. This feeling of being oneself was related to the fact that HIV was part of their identity: "I want to be myself and HIV is part of that" (R 119).</p> <p>As a model, respondents point to the "Swiss Perspective" (Het Zwitserse Standpunt), which states that PLWHA who take their medicines according to prescription, have an undetectable viral load and are free of sexually transmitted diseases and are practically not contagious in a monogamous sexual relationship. According to the participants this is important information that should be better known among the general public. When people start to see that HIV is noncontagious, and HIV is also publically addressed as something neutral or noncontagious</p> <p>public information should be presented featuring real HIV-positive people. One participant said, "Commercials with famous Dutch people do not work. It is a good thing that HIV is discussed, but it doesn't work, not really. People with HIV and their story that touches people, they can identify with these people" (R 52). Besides, these commercials should focus on all groups of people living with H</p> <p>They believe that when stigma is reduced they will be able to disclose their HIV-positive status to other people more easily, which will also make it easier for them to effectively self-manage their illness.</p> <p>By disclosing, the participants feel that they can educate people about HIV themselves. A Dutch campaign called "HIV uit de kast" (HIV coming out) is an example of PLWHA educating other PLWHA about disclosure to fight stigma.</p> <p>people will see what a person with HIV really looks like. One participant illustrated this point by saying</p> <p>"[I disclose] for educational motives . . . to show people we are not sick, we are not dying, and we are not contagious" (R 100). One participant, for instance, said that disclosing is the only way to "break the silence of HIV" (R 267). Another participant said that disclosure is a way to "fight prejudices" (R 335)</p>
EM17 DiGiacomo, M. et al. - 2015	<p>Women may adapt to changed capacity for physical function or symptom experiences rather than constantly attending to them and labeling them as illnesses</p>
EM17 DiGiacomo, M. et al. - 2015	<p>Ensuring understanding and facilitating communication are essential to women's empowerment, as explained by one participant:</p> <p>"Women really need to be empowered, and we all know that people feel comfortable in their first language, especially when they're older, because people regress to their culture</p> <p>other women on the phone, or at the shopping centre... It's this verbal, and I think if you cut that off, you're not giving women the tool that they use." (</p> <p>Health workers have to speak up for rights of women even in their own workplaces." (PS)</p> <p>"And there has to be a funding model where community support services are able to be funded as part of the health service, not separate. And, I think, outsourcing to NGOs (non-government organizations) is a good thing, in that you're empowering and building up the community sector, where do women mostly get their supports? - From the community sector. But there has to be a real link between both. So primary, secondary, tertiary care can only work well with a really supportive community sector." (PS)</p>
EM19 Bess, Kimberly D. et al. - 2009	<p>Tension 2: Partners versus Clients A central piece of the New SPECS project was to promote participation through building collaborative partnerships.</p> <p>Following recent trends in the field, staff members have begun to use the term customer implying a more contractual relationship between independent agents,</p>

	<p>Staff members however seemed most comfortable when using familial language such as our families, our parents, our kids, or simply people—to describe their relationships.</p> <p>The preference for framing actual relationships in familial terms over less personal terms (e.g., client or customer) suggests a discomfort with openly power-laden language, reflects the organization’s values of caring and acceptance, and is consistent with the parental role MLK plays as an authority in the community. One staff member summed it up as follows. MLK (is) like another paren</p> <p>In describing participatory practices in the youth program, a staff member explains. I pretty much let the kids decide the kind of the nature, just the atmosphere, (and) the culture of the classroom. As much power as they can give it as far as what they’re going to be able to do, what goes down, what doesn’t go down, the direction we go in, they pretty much set that by themselves. I know that’s the case of our classroom. They are customers...</p> <p>participation is understood to be a value for developing individual voice and choice,</p> <p>At MLK, staff members articulated the dissonance they experienced in their roles and the following passage of one leader suggests the beginning of an alternative framing that is intended to subvert dominant-subordinate patterns of role relationships but continues to honor the values of caring and helping.</p> <p>For me I really see that that is the process of what happens here, that people come, we accept them where they are, and that their process may take a very short time or it may last for years. And then I would say that my vision or my hope is that (person’s)...relationship to us changes. They are no longer needy in the sense—I mean, they may need things but in their own minds they now come as a friend.</p> <p>It takes a great deal of sensitivity and training to know how to build on other people’s views, and how to synthesize somebody else’s voices with our own.</p> <p>In each organization, the summer mini-projects were a response to members’ persistent push to move to action and the implementation</p> <p>MLK leader makes sense of the struggle in all its complexity and expresses hope, and a recognition of the need, for a new kind of participation:</p> <p>...maybe we got way too hung up on the perfect notion of the process, how this has to work itself out. In all our political correctness...having residents there, and that was to say, yeah, we had residents there, we did the right thing. And it was so obvious that you were so allowing it to be our process. But I think it was kind of hard to feel where to grab on sometimes. You know, there’s no happiness achieved in spoon-feeding us. We’d have been like, “Oh, my gosh, we knew this. Why are they going on and on and on?” So I don’t think there’s a wrong</p>
EN01 Ekundayo, Olugbemiga T. et al. - 2012	<p>Prostate Cancer prevention/care service facilities and providers</p> <p>legislative and policy advocacy</p> <p>Service education,</p> <p>Health literacy,</p> <p>Community problem prioritization</p>
EN02 Browne, Annette J. et al. - 2012	<p>Explicitly articulate the commitment to equity in the mission, vision and other organizational policy statement</p> <p>Key to positioning equity as an explicit mandate is the articulation of related commitments in governance, mission statements, and organizational-level policy statements.</p> <p>strong leadership within the organization</p> <p>activities of the organizational leaders are important in reinforcing the organization’s commitment to equity,</p> <p>leaders engage in within the wider communit</p> <p>I think to have it [a commitment to equity] as a shared value is very central to what we do</p> <p>Develop and advocate for structures, policies, and processes to support the enactment of equity</p> <p>Funding and policy environments</p> <p>leaders must develop appropriate structures, policies and processes within their organizations</p> <p>stable funding arrangements</p> <p>Centre leaders were active at local community, city, provincial and federal levels advocating for adequate social housing, better access to income supports, and allocation of health care funding</p> <p>scheduling structures need to be creative, fluid, and innovative to accom-</p> <p>To address the health effects of persistent power inequities, stigma, everyday social exclusion, and systemic discrimination experienced by many marginalized patients, organizations must first reflect critically, and purposefully, on power relations within their organization</p> <p>to discuss possible anti-racist approaches.</p> <p>We’re not just a number</p> <p>recognize that many people have experienced the inter-generational effects of systemic and individual discrimination and racism</p>

	<p>Enhance access to resources that address the social determinants of health with an emphasis on advocacy and inter-sectoral collaborations</p> <p>Maintaining or improving health is dependent on access to adequate safe housing, adequate nutrition, and meaningful activities.</p> <p>Fostering connections with individuals, groups and resources</p>
EN10 Brooks, Fiona - 2008	<p>The councillors all stated that they joined the council with clear ideas about how services could be developed, based primarily from observations drawn from their own or their families experiences of receiving car</p>
EN14 Hirjaba, Marina et al. - 2015	<p>responsibility sharing initiatives that could improve care between patients and healthcare professionals</p>
EN17 Bailey, Kenneth Chase et al. - 2014	<p>education for the youth, safety for all, housing permanence and security, stability of the neighborhood, and reliable leadership</p> <p>Recognizing the environmental difficulties and uncondusive lifestyles faced by the children and families in these neighborhoods is beneficial in understanding why the health initiatives intended for these communities may be struggling</p>
EN18 Mitchell-Brown, Fay et al. - 2017	<p>access to care is dependent on financial, organizational, and social or cultural barriers. Utilization of services is dependent on affordability, physical accessibility, and acceptability of service</p>
EN19 Garcia, Jonathan et al. - 2015	<p>need for more community-engagement to address violence against LGBT persons, programs that help clients find work and housing had more of an impact on their lives than testing commitment to policymaking and funding focused on capacity building to sustain safe spaces as integral to promoting HIV prevention</p>
EN20 Pinto, Rogério M. - 2009	<p>we're making something happen that matters together</p> <p>more assertive, more empowerment as a result of the collaboration.</p>
EN25 Robinson, Nicola et al. - 2015	<p>Organizational commitment to patient and public engagement (PPE), i.e. PPE being built into policies; having dedicated staff and money for on-going, formal PPE</p> <p>Changing NHS philosophy, which doesn't currently focus on 'customer' service</p> <p>Overcoming the barrier of stigma</p>
EN28 Safo, Stella et al. - 2016	<p>give them back the [study] results so that they can feel more empowered, so that they can develop trust</p> <p>structural change</p>
EN34 Natale, Anthony P. - 2009	<p>desire for ongoing community updates on HIV/STI and other men's health trends was expressed</p> <p>I think that black folks need to start taking care of each other.</p> <p>enhanced racial identity and imagined being able to make health linkages there</p>
EN40 Rise, Marit By et al. - 2013	<p>(...) where both parties feel respected and not overruled. Both must be allowed to say what they think and feel</p> <p>That was the very first thing I said when I was asked to be a public representative. They have to listen to us. [...] We are supposed to be in an advisory committee for the management and the hospital board. And the day I feel they arent listening to us I will walk away</p>
EN45 Young, C. et al. - 2016	<p>to inform their local community of data that showcased positive health gains</p>

Table 33 - Empowerment barriers

CO06 Graves, K. et al. - 2011	<p>I don't think African American women are as proactive as White women</p>
CO08 Dowling, Joni E. - 2010	<p>I have no job security and no vacation time</p>
CO37 Taylor, Elizabeth et al. - 2014	<p>being interpreted generically as "nurses" or "exercise" could emphasise the medical model or physical impairment-based approach prevalent in some cultures.</p>
ED9 Santos-Livengood, Christie A. - 2015	<p>sexual fetishization, or racially motivated objectification, experiences of strangers approaching them with the assumption that they are "foreign."</p> <p>straight individuals view bisexual women as personally threatening to their relationships and heterosexuality</p> <p>bisexual participants experience social ostracism from both queer and straight people, and are hypersexualized, or perceived as overly sexual and unethical in their sexual behavior</p> <p>Based on heterosexist assumptions of their straight sexual orientation, participants described feeling conflicted between authenticity and safety.</p>

	<p>navigating multiple identities while interacting within social and ecological contextual factors.</p> <p>challenges in navigating expectations and contexts, and the heteronormative structures</p> <p>“A lot of my female partners have been sexually violated in the past, raped of some sort, so that certainly kind of – I find that might be more unique for women to women or women trans relationships because in terms of rape, more women are raped than men... I</p> <p>childhood sexual health education with Catholic fear- and shame-based tactics.</p> <p>the sexual health education they did receive was limited to safer sex in the context of heterosexual behaviors. P</p> <p>be more prepared, be more assertive in that moment.”</p> <p>Bisexual participants were not as familiar with safer toy materials, or barriers with which to use with them.</p>
EM02 Miller, Robin Lin et al. - 2012	<p>Detroit is not typically viewed by members of Mpowerment Detroit as gay-friendly. Mpowerment</p>
EM05 Oliffe, John L. et al. - 2008	<p>Two parts of the conference related specifically to PCSG sustainability issues. First, a roundtable discussion explored strategies to more effectively communicate between groups and formalize an affiliation with the BCFPD to support and guide the activities for all BC-based PCSGs. Although attendees supported the ideas presented, no agreement or resolution was made. By choosing not to formally unite, many groups remained separate and independent, and this had implications for some groups’ sustainability because, in essence, they had forgone the BCFPD’s offer to provide free resources and support.</p> <p>In addition, the lack of solidarity reduced the collective power and capacity to negotiate rewarding affiliations with professional organizations.</p>
EM09 Grande, Stuart W. et al. - 2013	<p>Participant 5, whose experiences were legitimated by others interviewed, talked about how negative interactions with law enforcement reinforced his sense of vulnerability and suspicion of the world around him.</p>
EM16 Vries, D. H. de et al. - 2016	<p>he was not welcome in the home of some friends anymore after telling them about his status, while the dentist refused to treat h</p> <p>“[Due to my HIV] I have the feeling that I am worthless”</p> <p>“I don’t disclose because of the stigma that gets stuck to you if you do” (R 271); “I don’t disclose out of fear that people will reject me or will give an odd reaction” (R 161); or “I think that disclosure is synonymous to social exclusion and therefore infinite loneliness” (R 255)</p> <p>Selective disclosure can bring one’s self-esteem back and empower people as a way to gain social support and be freed from a secret. Yet, stigma influences disclosure negatively as experiences with or the fear of stigma motivates a nondisclosure, both selective or completely. Both forms of nondisclosure create relative silence about respondents’ HIV-positive status, which allows the high HIV-related public and structural stigma within the Dutch society to remain existent.</p> <p>Participants felt that stigma has to be reduced in order for them to be able to openly and without fear speak about their HIV-positive status to others.</p> <p>Lack of visibility of stigma reduction programs was notably observed.</p> <p>“I never hear about them. And if I don’t hear about them, the rest of the world will definitely not hear anything about them either” (R 215)</p> <p>“There were a lot more media campaigns in earlier days . . . now this has changed for the worse” (R 182).</p> <p>he programs that do reach the general public also create dissatisfaction among the participants. The main reason given for this is the fact that campaigns that try to reduce stigma actually often contribute to a double stigma for PLWHA.</p> <p>“Commercials on the television about HIV are always filled with dark-skinned people. You never see White people. Or they only show gay men. We have to break the taboo” (R 139)</p>

	<p>concerns about the fact that HIV, when presented in the media, is always about other countries, and not about the Netherlands. One participant, for example, said “I do not see a lot of commercials that try to reduce stigma, especially not of HIV-related stigma in the Netherlands” (R 92).</p>
<p>EM17 DiGiacomo, M. et al. - 2015</p>	<p>doctors attributing presentations to mental health issues, concerns over labeling and stigma, generational and cultural communication and socialization norms, Anglo-dominated world views and language, education level, time restrictions and comorbidities, and misconceptions of English language mastery.</p> <p>Dismissal and attribution of concerns to mental health problems</p> <p>women she works with may avoid seeking help or may lie to minimize financial shortfalls when unable to refill prescriptions for fear of being labeled and stigmatized.</p> <p>women’s perception of being dismissed by doctors who perhaps do not appraise their complaints as requiring investigation.</p> <p>Women’s disempowerment around communicating with health professionals</p> <p>a the dominance of men in health</p> <p>When asked to elaborate on what was meant by disempowerment, one participant related it to not seeking second opinions. Reasons for this were multifaceted and may reflect cultural, geographic, logistic, financial, transport, and caregiver role barriers.</p> <p>Disempowerment was also discussed in relation to inhibited dialogue with health professionals.</p> <p>“...older women treat doctors like little gods up to a point</p> <p>“Women used to come in and tell us things, a lot of things, you know, about their local doctors and how they didn’t listen to them, that’s a major one. And how they just pushed them off as long as they got them out of the place in five minutes...they would write a script, especially with women with menopause, they were the main complainants...</p> <p>“People who are stuck, like, they migrated 30 years ago and the cultures over there have changed, but they haven’t. They’re, sort of, stuck in that patriarchal, sort of, mindset.” (PS)</p> <p>I think the whole idea of chronic health conditions is so Anglo, I’m really sorry to say...Instead, women from different cultural communities adapt to having what we term as ‘chronic conditions’ and don’t identify as such...</p> <p>In cases where there is intimate partner (or other domestic) violence, which was described as under-reported in the study region and represented a significant deficit in relation to needed supportive services, also had carried financial implications for women thinking of leaving a violent relationship.</p> <p>“More likely to be poverty stricken if you go it on your own” (PS)</p> <p>An important consideration is that not everyone in need meets the eligibility requirement for formalized support and services. Participants shared that women caring for children and fleeing from violent relationships face disadvantage as they or their children do not always qualify for protection.</p>
<p>EM19 Bess, Kimberly D. et al. - 2009</p>	<p>Active</p> <p>Although this was the goal, we observed very few examples of this type of participation in these two organizations</p> <p>Passive</p> <p>These were, by-and-large, willing and engaged participants in the process. They openly discussed their experiences of dissonance but were not fully committed to change. They valued participation in theory but may not have had any or much experience with participatory processes in which many different stakeholders come to the table as partners.</p> <p>Passive-Resistant</p> <p>Some individuals who participated in a passive resistant way were deeply embedded in the current paradigm and believed that more of the same was the best or only path to community change. These individuals saw their work as saving those who wanted to be saved. Other project members felt powerless, and although they were present during project meetings, they were non-participants.</p>

What was far more challenging for participants was to take the values inherent in partnering

put them into practice by expanding these initial partnerships to include community members and other stakeholders.

within the context of the project it was imperative that both groups over time view community members more as partners and less as clients. The risk of not doing so was that community members whose participation was initially more passive or tokenistic (i.e., attending project meetings as invited guests) might move in the direction of non- participation (where they assumed only the role of client or dropped out of the project) instead of toward political or active participation.

...participation in decision making by community residents... What does that mean, and how does it happen? ...I was really intrigued...about our first run at inviting community members to our table when we hadn't decided what it was that we were going to do. And the question became if it's really about bringing them to the table, then do we design that work around them and their input? And what is our capacity to do that? And what happened is we found out that's really not our capacity

the dominant-subordinate role structure is being played out in service provider/recipient, professional/client, parent/child, and teacher/student relationships.

interviews and focus groups, staff members rarely use the term partner to frame relationships with community members and few among them articulate their work in terms of co-learning or co- creating

the term "patient" was almost universally used in focus groups and interviews to describe relationships with community members even though the organization

he term "patient" is the least empowering and most limiting of the relational terms used in that the power differential implied

at Healthy City the greatest challenge to participation did not involve community members but rather was related to the internal power dynamics between members

staff were striving to empower community members but were unable to overcome the challenges of the dominate-subordinate language or practices embedded in the ameliorative paradigm

In describing youth as customers the staff is symbolically effecting a shift in the framing of traditional youth- staff relationships as a way of promoting participation and empowerment, but later in the same discussion around the program's mission, they revert to a world view consistent with the ameliorative paradigm when they use the term "renorming" to describe how staff members understand their role with youth in their program.

In both organizations patterns of role relationships are maintained and controlled within the system and play out both benevolently (e.g., parent-child, giver-receiver), but also on occasion as authoritarian, and in this case, the experience of those in the subordinate position is of oppression.

Tension 3: Surplus Powerlessness versus Collective Efficacy

This tension relates to pervasive powerlessness, particularly in Healthy City, that characterized staff members' relationship to their own agency in effecting change in their organization and in the community

The most explicit form of powerlessness within Healthy City was the feeling of isolation and exclusion by staff members and viewing power as a "zero-sum" gam

Healthy City relations among staff were invariably portrayed as us (i.e. the powerless staff) and them (i.e., the powerful leadership). This culture of "dominate" or "be dominated" left little ground for building collaboration even among staff members. Members tended to view themselves as independent agents trying to survive

some self-censoring occurred due to fear of "opening your mouth" too much and antagonizing senior leadership. This fear positions staff members as vulnerable and subject to concrete or intangible negative repercussions

	<p>Capacity and skills to engage in a participatory process constitutes the final contribution to surplus powerlessness.</p> <p>It is hard to learn how to participate with others in a symphony of voices, as opposed to solo performance</p> <p>In Healthy City, where members tended to work very independently and had a very clear sense of what was and was not within their job description, collaboration toward collective ends was not part of the culture.</p> <p>Within HHSOs collective reflection and learning processes are not widely understood as participatory practices in which beliefs and assumptions can be challenged and explored. Furthermore, it is not understood how these practices, in turn, can lead to building shared values and goals</p> <p>‘We don’t sit around talking about what to do. We just do it...We’re social workers. We don’t plan, we do.’</p> <p>HHSOs feel pressure to maintain funding to “keep the doors open.” Since donors fund action not process, reflection is seen as risky and costly</p> <p>Many staff members are not cognizant of the detrimental effects of acting without a clear sense of their own values and agenda within the community. Summer projects sponsored by each organization’s T-team highlight this ongoing struggle and the costs associated with not creating a reflective environment.</p> <p>The patterns of passive participation described above mirror ongoing dominant-subordinate role relations that are the hallmark of the ameliorative paradigm and are complicated by intra- and inter-organizational dynamics.</p>
EN02 Browne, Annette J. et al. - 2012	<p>At the level of direct clinical care, mission and vision statements also provide a sense of perspective</p> <p>will not be sustainable without supportive funding and policy environments.</p> <p>dismissiveness, stereotyping and negative assumptions related to poverty, racism, substance use and mental illness</p> <p>what might be seen as excellent interpersonal communication in one cultural context might be seen as discriminatory or alienating in another.</p> <p>Disempowerment and alienation of marginalized groups in society are major obstacles to achieving health equity</p>
EN10 Brooks, Fiona - 2008	<p>I think there is a fundamental misunderstanding about patient participation because we’re just about to advertise our patient advocacy and liaison services facilitator and I’ve had numerous enquiries from people who believe that they have extensive experience in patient participation because they’re a nurse or because they’re a doctor, or because they are a therapist</p>
EN17 Bailey, Kenneth Chase et al. - 2014	<p>three primary causes for health disparity: city master plan, urban renewal, and economic displacement (relocation of community members by state agencies to allow for construction)</p> <p>abandoned homes, vacant lots, extensive safety precautions on homes and businesses (burglar bars and security doors), nonexistent side-walks (or those in need of repair), few businesses geared toward healthy living, many places of worship, and an obvious distinction between government- and university-owned property and the surrounding neighborhood</p> <p>lack of collaboration, lack of perceived access to health (e.g., initiatives are not meant specifically for them), minimal investment in the community, and unwillingness to listen to the community</p> <p>felt a sense of being overlooked</p> <p>minimal investment in the community,</p> <p>the community could be manipulated to benefit the efficiency of the community decision-makers, those elected officials and individuals in charge of government-run programs, but not necessarily benefitting the community</p> <p>They don’t care about the need</p> <p>there is so much and well-deserved mistrust</p>

	<p>very distrustful ... [of] government, you lose neighborhood, you lose community, you lose the pride that exists. This was a homeowner-dominated area when I grew up, now it's a rental-dominated neighborhood, so people have no family association. In education, lack of diversity Persistence of racial tension. sense of helplessness or "inability to break the chain" to improve their environment, their health, and take advantage of health initiatives. loss of community pride. the community's feeling they are on the "wrongside of the tracks"</p>
EN19 Garcia, Jonathan et al. - 2015	<p>conformity is socially policed, It's threatening to be with a feminine man.. Men reported experiencing institutional stigma and discrimination because of their race, sexuality, socioeconomic class, and gender performance. sinners denied their homosexuality at church to "feel like they belong" and thus to maintain social ties with the church. the lack of support from key social institutions, such as churches and their families, reduced their feelings of self-worth and rendered them more vulnerable to HIV, drug use, and limited educational and employment opportunities</p>
EN20 Pinto, Rogério M. - 2009	<p>. The researcher was interested in numerical things . . . we were more interested in the contextual situation</p>
EN24 Powell, Rhea E. et al. - 2016	<p>social determinants of health that limited their patients' ability to manage their health including: insurance issues; financial barriers; mental health and substance abuse; and housing and transportation need feel that's their life. It's constant crisis and so that's how they treat it. That's why they go through the [emergency departments], the health centers</p>
EN25 Robinson, Nicola et al. - 2015	<p>we can rely on the great British tradition of volunteerism, but usually that means, again, you're back into certain socioeconomic groups The most frequently cited under-engaged group were BME, due to stigma, specifically Bangladeshi; Muslim; African (especially Sub Saharan/Horn of Africa/Afro Caribbean); Eastern European; South Asian African people, I'm afraid to say, ah tend to come with social conservatism, and I am thinking here of homophobia the NHS is essentially a Stalinist type organization, it's very, whether locally or on a national level, depending on what you're trying to engage in, it is very centrally driven, from ivory towers like this one (P4, Commissioner)</p>
EN28 Safo, Stella et al. - 2016	<p>lack of sharing information reinforced an imbalance of power i</p>
EN32 Hogden, Anne et al. - 2012	<p>restricting the funding of dedicated specialist ALS health professional positions; limiting clinic resources, such as production of evidence-based clinical guidelines; limiting patient numbers with access to specialist clinics; and curtailing health professional education and awareness of the specific needs of people with ALS</p>
EN33 McDonald, Ruth et al. - 2008	<p>the definition of empowerment implicit in many nurses' accounts was a process in which patients took on board instructions from nurses and followed them to the letter. It's their choice to be non-compliant ... I empower them with that privilege of saying "yes" or "no". If they're continually non-compliant and you've gone through all the nice approaches ... you've got to go to the bottom line which I don't, no one likes doing but sometimes you have to use those, not threatening that's not the word ... shock tactics (Far from respecting patients' autonomy, or attempting to see things from their perspective, nurses' accounts conveyed a battle of wills, with nurses attempting to impose on patients their views of appropriate conduct intended to shock patients into seeing the error of their ways</p>
EN34 Natale, Anthony P. - 2009	<p>I think that they need to talk about it more in the church. ... They talk about black on black violence and talk about missing babies daddies, but they don't talk about AIDS</p>

EN39 Durme, Thérèse Van et al. - 2014	the role of patient organizations is too weak
	the predominant system is fee-for-service, which may lead to (a) a push for quantity and professional stress and (b) difficult task delegation, because the professional who is delegating is not paid if another care provider delivers the health care
	There are too few housing facilities; we are regularly confronted with demands from people we are unable to even enroll on a waiting list.”
EN42 Fairbrother, Peter et al. - 2013	Healthcare professionals considered 'patient empowerment' resulting from self-management as beneficial, so long as patients exercised personal responsibility over health and lifestyle choices within medically acceptable parameters. F
EN45 Young, C. et al. - 2016	Aboriginal health data predominantly reflected poor outcomes

ANNEXE 5 : The role of IT tools and the Internet – Quotations and codes

Table 34 - IT tools as facilitator for finding health information

CO08 Dowling, Joni E. - 2010	<p>the Internet as their primary resource</p> <p>used the Internet to assist her decision making. In her research, she found a test called CYP2D6,</p> <p>Cancer Society (www.cancer.org), Breast Cancer.org (breastcancer.org), Susan G. Komen (www.komen.org), and Young Survival Coalition (youngsurvival.org), to get information to assist them in making decisions. Y</p> <p>The first thing I did was cruise the Internet</p> <p>It was a great help. I knew what my options were from researching it on the Internet.</p> <p>active member of a BreastCancer.org blog where women talked about their treatment, which helped her</p> <p>to distribute a recommended list of Internet Web sites.</p> <p>wished for a list of recommended Web sites to assist women in the decision- making process</p> <p>I read the Internet and asked peers, then wrote down questions for the next time I saw the oncologist.</p> <p>I read the Internet and asked peers, then wrote down questions for the next time I saw the oncologist.</p>
CO23 Davies, Jane et al. - 2014	<p>preference for an electronic format</p> <p>interactive pictures and less text.</p>
CO27 Dolce, Maria C. - 2011	<p>online support group</p> <p>e-mail contact with persons who answered my questions, helped reduce my fear, and helped me come to terms with my diagnosis</p> <p>the Internet to diagnose themselves</p> <p>a lack of informational support related to procedures and were better prepared after seeking information on the Internet</p> <p>Another survivor found reading blogs written by other patients who had experienced a procedure to be helpful and wrote, "I could better relate to their experience and it helped to know what to expect from a physical and emotional perspective."</p> <p>found help from their online communities</p> <p>Stories were shared about needing "emotional support" and turning to online communities.</p> <p>grateful for the Internet</p> <p>The Internet allowed me to track down a couple of journal articles relating to this [off-label] use, which helped persuade my doctor</p> <p>Thanks to the Internet, I pushed for what my daughter needed</p> <p>Cancer information verified through online resources influenced survivors' choices and care decisions.</p> <p>I was able to get information about treatment of carcinoid that conflicted with what my oncologist said— so I sought several specialists' opinions and they all agreed, but conflicted with the oncologist</p>
CO31 Zulman, Donna M. et al. - 2015	<p>tools that could provide information about their multiple conditions, such as websites</p> <p>Online resources that consolidate information about MCCs</p> <p>Bundled apps for MCCs</p> <p>Online support groups</p> <p>Many patients had experience using technology to detect potential medication interactions</p> <p>...tried to arm myself with enough information with the technology, with the right care providers so that I control the disease; the disease doesn't control me</p>

	patients desired resources that consolidate and synthesize information about MCCs, such as applications that help identify potential medication-medication or condition-medication interactions.
CO32 Greenhalgh, Trisha et al. - 2010	One participant who had tried HealthSpace, later became interested in downloads for a digital personal organiser (iPhone apps) and found these more fit for purpose than HealthSpace. online self help group hosted by a charity for patients
CO33 Vilhauer, Ruvanee P. - 2014	it was great having a support network, you know, in my computer room When I wanted to interact with people and when I didn't, it was totally under my control. information is still there it's a treasure trove
ED9 Santos-Livengood, Christie A. - 2015	receiving their sexual health knowledge from the Internet, friends and health care providers, and trust their doctors above other sources
EN04 Cook, Catherine - 2012	I think online talking is very good as you can speak to people in the same situation who are having the same problem The internet has been my most used resource about HSV. It's available 24 hours a day to answer any questions I have. It I found the herpes website to be most informative as the doctor is too expensive just to go to for a chat
EN05 Graffigna, Guendalina et al. - 2014	s I search the Internet in order get answers."
EN34 Natale, Anthony P. - 2009	MSM suggested that education efforts highlight physical, psychological, economic, social, and sexual effects of living with HIV disease. One suggestion involves creating a method, perhaps for the Internet, for MSM to assess how HIV impacts the lifespan, I am not sure how you would do this, but education on the Internet would help. Not questions that people can read and sift through the information. I think that it needs to be more specific. Like what are the risks for oral sex, and what are the risks for anal sex.
EN35 Gien, Lan et al. - 2017	foods mentioned in the internet are not available locally "Some of the things they suggest you eat is things that I haven't heard of", "You'll never find it (in this province)".
EN37 McCabe, Catherine et al. - 2014	distinct lack of online information related specifically to the Irish conte I've been on the British Lung Foundation and different sites on the Internet but they do not give a proper breakdown of things. And most of it is American, which is different to us, they have different facilities to use a Another thing about people on the internet you know at least if you look up what other people are going through you think oh I'm not that bad or you know it can make life a bit more bearable because during winter months I'm more or less indoors."
EN45 Young, C. et al. - 2016	Data collected from the participant's own ACCHS, or from the local area, was often trusted more than data derived from more distal sources

Table 35 - ICT Barriers

CO08 Dowling, Joni E. - 2010	they advised me not to go on the Internet because of getting overwhelmed with information
CO27 Dolce, Maria C. - 2011	lack of clinical expertise in treating their disease and, consequently, turned to the Internet
CO32 Greenhalgh, Trisha et al. - 2010	The 21 people in this substudy who tried using HealthSpace found it of limited value. None entered any health data on to it and none intended to continue using it in its present form, although some anticipated that a future upgraded version might be more worth while
EN01 Ekundayo, Olugbemiga T. et al. - 2012	disparity in health information access for African Americans
EN04 Cook, Catherine - 2012	to decipher the research that is out there and filter out the propaganda and fear-based support groups (V

EN15 Maten-Speksnijder, Ada J. et al. - 2016	the mother says: 'I don't believe Femke really understands what is going on with her and the disease'. Femke reacts: 'I do understand, but I don't believe the half of it.' The NP shows Femke where she can find a lot of information about the disease on the Internet. She explains: 'this could be helpful to explain to others what it means to have rheumatoid arthritis.
EN32 Hogden, Anne et al. - 2012	The Internet is so varied, that, we have patients regularly sending in information going, 'Oh, I've found this amazing machine that's going to solve all my problems'. And having to tell them, 'I realize you've found this and all the things sound really good, like online there's all these wonderful reviews about this system, but it doesn't work'."

Table 36 - General IT tools

CO08 Dowling, Joni E. - 2010	<p>the Internet as their primary resource</p> <p>used the Internet to assist her decision making. In her research, she found a test called CYP2D6, which determines how individuals metabolize Tamoxifen. YWWBC2 also used the Internet. She found an article indicating individuals like herself, whose diagnosis was DCIS comedo, needed an additional pathology staining to determine whether parts of the cancer were invasive</p> <p>Most women used Web sites like Web MD (www.webmd.com), American Cancer Society (www.cancer.org), Breast Cancer.org (breastcancer.org), Susan G. Komen (www.komen.org), and Young Survival Coalition (youngsurvival.org), to get information to assist them in making decisions. Y</p> <p>The first thing I did was cruise the Internet</p> <p>It was a great help. I knew what my options were from researching it on the Internet. they advised me not to go on the Internet because of getting overwhelmed with information</p> <p>active member of a BreastCancer.org blog where women talked about their treatment, which helped her</p> <p>to distribute a recommended list of Internet Web sites.</p> <p>wished for a list of recommended Web sites to assist women in the decision-making process</p> <p>I read the Internet and asked peers, then wrote down questions for the next time I saw the oncologist.</p>
CO23 Davies, Jane et al. - 2014	preference for an electronic format interactive pictures and less text.
CO27 Dolce, Maria C. - 2011	<p>lack of clinical expertise in treating their disease and, consequently, turned to the Internet</p> <p>online support group</p> <p>e-mail contact with persons who answered my questions, helped reduce my fear, and helped me come to terms with my diagnosis</p> <p>turned to the Internet to diagnose themselves</p> <p>a lack of informational support related to procedures and were better prepared after seeking information on the Internet</p> <p>Another survivor found reading blogs written by other patients who had experienced a procedure to be helpful and wrote, "I could better relate to their experience and it helped to know what to expect from a physical and emotional perspective."</p> <p>found help from their online communities</p> <p>Stories were shared about needing "emotional support" and turning to online communities.</p> <p>grateful for the Internet</p> <p>The Internet allowed me to track down a couple of journal articles relating to this [off-label] use, which helped persuade my doctor</p> <p>Thanks to the Internet, I pushed for what my daughter needed</p> <p>Cancer information verified through online resources influenced survivors' choices and care decisions.</p> <p>I was able to get information about treatment of carcinoid that conflicted with what my oncologist said— so I sought several specialists' opinions and they all agreed, but conflicted with the oncologist</p>

<p>CO31 Zulman, Donna M. et al. - 2015</p>	<p>I can save myself easily 15 or 20 visits a year just by messaging my [providers] tools that could provide information about their multiple conditions, such as websites have it consolidated in one place^ and mobile devices Bpreloaded with apps that help with certain conditions. Patients also desired task management applications that crossed health care systems: Blt would be great if I could just get a monthly reminder that I could print out what was happening this month at all my different [clinics].^</p> <p>Online resources that consolidate information about MCCs</p> <p>Bundled apps for MCCs</p> <p>Organizational apps and web-based programs to assist with complicated medication regimens</p> <p>Centralized reminder system that integrates information from different health care systems</p> <p>Apps and web-based programs that communicate self-management practices to provider</p> <p>User-friendly automated reminder systems about daily self-management activities</p> <p>Online support groups</p> <p>Many patients had experience using technology to detect potential medication interactions</p> <p>the telecommunication, would save time, money, effort, miscommunication, a missed appointment, confusion, frustration...</p> <p>technology in these situations to research their health conditions and actively participate in health care decisions</p> <p>technology empowered them in their role as advocate</p> <p>...tried to arm myself with enough information with the technology, with the right care providers so that I control the disease; the disease doesn't control me</p> <p>patients desired resources that consolidate and synthesize information about MCCs, such as applications that help identify potential medication-medication or condition-medication interactions.</p> <p>Patients expressed interest in resources that would provide high-quality mobile app Bbundles^ that address their specific conditions as well as apps that provide assistance with common self-management challenges (e.g., complicated medication regimens) and integrate information from different health care systems (e.g., appointment reminders).</p> <p>patients described a need for online resources that would connect them with patients who had similar MCC profiles and support their roles as experts and advocates.</p> <p>videoconferencing and other tools (e.g., mobile apps) that would facilitate caregiver participation and engagement in their care</p>
<p>CO32 Greenhalgh, Trisha et al. - 2010</p>	<p>Strategic and business cases for HealthSpace did not mention patients' expectations of personal electronic health records, motivation to use them, or current self care practices.</p> <p>The main experts identified in strategy documents were software developers and national implementation leads; neither clinical nor patient expertise was mentioned</p> <p>A lengthy risk assessment focused exclusively on technical and procedural risks (such as "inadequate specification of requirement by NHS," "information governance and data security requirements [may] change," and even that uptake of Health-Space accounts would outstrip capacity to process applications⁴⁰). Risks linked to people's feelings, motivation, and values (for example, lack of interest or a perception by patients that the software was not helpful) were not listed.</p> <p>The 21 people in this substudy whotried using HealthSpace found it of limited value. None entered any health data on to it and none intended to continue using it in its present form, although some anticipated that a future upgraded version might be more worth while</p> <p>did not see basic HealthSpace as adding value in managing their condition</p>

	<p>t self monitoring of health data involves a complex interaction between patient and clinician and that the process of entering and accessing data cannot be meaningfully separated from the wider care relationship</p> <p>the "sleeping gym membership" phenomenon: registering for HealthSpace, accessing it once, then losing interest.</p> <p>Three of the 20 agreed to try HealthSpace, all of whom abandoned it soon after first accessing it and declared that they were not interested in using it again</p> <p>Some people in this subsample had no access to computers or the internet at home.</p> <p>participants saw these technologies as serving other purposes in their lives (games, shopping, social net- working).</p> <p>Some were already using or exploring other ways of documenting and monitoring their condition, such as paper (especially the widely used blood glucose diaries supplied free by manufacturers of monitoring devices) or bespoke software (for example, Excel spreadsheet)</p> <p>One participant who had tried HealthSpace, later became interested in downloads for a digital personal organiser (iPhone apps) and found these more fit for purpose than HealthSpace.</p> <p>online self help group hosted by a charity for patients</p>
CO33 Vilhauer, Ruvanee P. - 2014	<p>Gs. Women who lived in rural areas with- out easy access to FTFGs, and women who had difficulty attending FTFGs because of illness symptoms or treatment side effects</p> <p>it was great having a support network, you know, in my computer room</p> <p>When I wanted to interact with people and when I didn't, it was totally under my control.</p> <p>it took me so long to read the mail, that by the time it came for me to write, I was too tired to write</p> <p>with online support, there's chances that you could find somebody at 2 and 3 in the morning that you can talk to."</p> <p>messages could be read long after they had been sent.</p> <p>information is still there</p> <p>it's a treasure trove</p> <p>support was constantly available</p> <p>more opportunity for getting their concerns heard</p>
CO38 Duineveld, Laura A. M. et al. - 2016	<p>System to schedule patient visits</p> <p>They requested a system to call patients for scheduled visits, because they feared follow-up appointments would be forgotten by patients and/or themselves.</p> <p>time investment should be assessed in advance, to determine whether it is feasible.</p> <p>patients would gain insight into their own symptoms and concerns</p> <p>the use of eHealth in general as they found it impersonal, and preferred exploration of symptoms and concerns by themselves</p> <p>eHealth would only be suitable for patients who are highly educated and young. The elderly, poorly educated people, people with no computer skills, illiterates and immigrants who are not able to understand</p> <p>the use of Oncokompas2.0 could cause arousal in patients, by showing them a list of problems that could occur.</p> <p>empowered</p> <p>relieve the workload of GPs</p> <p>Increased insight for both GP and patients in case of vague symptoms and problems</p> <p>Impersonal</p> <p>Not suitable for all patients</p> <p>Increases patients' awareness of problems</p>
ED10 Costello, Joanne F. - 2013	<p>So the technology isn't there for this to be managed perfectly</p>
ED11 Dale, Jeremy et al. - 2008	<p>telecare supporters indicated that they all enjoyed helping others and derived personal benefits, such as improved knowledge, attitudes, skills, social relationships, and insight</p>

	d helped them implement lifestyle changes, such as regular exercise, healthier diet and weight loss.
ED9 Santos-Livengood, Christie A. - 2015	receiving their sexual health knowledge from the Internet, friends and health care providers, and trust their doctors above other sources
EM10 Peterson, Jennifer L. et al. - 2012	Support groups that meet online are increasingly being used the online group allowed him to connect to people who he perceived to be similar to him, this participant did wish for the face-to-face contact that some (but not all) members of the group were able to experience.
EM12 Wiljer, David et al. - 2013	he effectiveness of using eCancer as an interface to creating a survivorship care plan (results reported in another manuscript) was helpful for some participants with their feelings of 'being rushed' by providing structure and keeping the clinician and participant more focused on the conversation
EN01 Ekundayo, Olugbemiga T. et al. - 2012	f technology including DVDs should be limited as many people might not have the hardware to use DVDs technology divide between this low income community and the rest of America represents a continuous source of disparity in health information access for African Americans
EN04 Cook, Catherine - 2012	When I used the internet I didn't have to worry about anyone seeing me as I have a laptop at home I think online talking is very good as you can speak to people in the same situation who are having the same problem The internet has been my most used resource about HSV. It's available 24 hours a day to answer any questions I have. It I found the herpes website to be most informative as the doctor is too expensive just to go to for a chat ...it has been through my own research on the internet, some good, some bad to decipher the research that is out there and filter out the propaganda and fear-based support groups
EN05 Graffigna, Guendalina et al. - 2014	s I search the Internet in order get answers." a mobile tool, or a website that you can use whenever you need, to communicate I would like to have a remote control, a kind of telemedicine tool to feel controlled and supported
EN15 Maten-Speksnijder, Ada J. et al. - 2016	mother says: 'I don't believe Femke really understands what is going on with her and the disease'. Femke reacts: 'I do understand, but I don't believe the half of it.'
EN19 Garcia, Jonathan et al. - 2015	They felt there was a contradiction that on the one hand the center had reduced its opening hours because of funding cuts, but on the other hand the center was expanding its computer lab
EN30 Cook, Erica J. et al. - 2014	NHS Direct users had a good awareness and un-derstanding of the service I've heard about it it's supposed to make life easier None of the NHS Direct 'users' were concerned that it was not a face-to-face ser-vice. In fact, many 'users' highlighted that they preferred the lack of face-to-face contact, and viewed the service as both personable and professional which provided them with the level of reassurance they needed.
EN32 Hogden, Anne et al. - 2012	The Internet is so varied, that, we have patients regularly sending in information going, 'Oh, I've found this amazing machine that's going to solve all my problems'. And having to tell them, 'I realize you've found this and all the things sound really good, like online there's all these wonderful reviews about this system, but it doesn't work'."
EN34 Natale, Anthony P. - 2009	MSM suggested that education efforts highlight physical, psychological, economic, social, and sexual effects of living with HIV disease. One suggestion involves creating a method, perhaps for the Internet, for MSM to assess how HIV impacts the lifespan, I am not sure how you would do this, but education on the Internet would help. Not questions that people can read and sift through the information. I think that it needs to be more specific. Like what are the risks for oral sex, and what are the risks for anal sex.

EN35 Gien, Lan et al. - 2017	foods mentioned in the internet are not available locally “Some of the things they suggest you eat is things that I haven’t heard of”, “You’ll never find it (in this province)”.
EN37 McCabe, Catherine et al. - 2014	<p>distinct lack of online information related specifically to the Irish conte</p> <p>I’ve been on the British Lung Foundation and different sites on the Internet but they do not give a proper breakdown of things. And most of it is American, which is different to us, they have different facilities to use a</p> <p>ICT use (%) Standard mobile phone (91%); smart phone (25%); desktop home computer (25%); laptop (25%</p> <p>Internet connectivity (%)</p> <p>Have access to Internet based resources (50%); have access to an Internet connection (53%); use Internet daily (25%); use Internet a few times a week (9%); use Internet a few times per month (6%</p> <p>Confidence in ICT use (%)</p> <p>Fully confident (50%); partially confident (16%); neutral (12.5%); not confident (6%); nonrespondents (16%)</p> <p>Another thing about people on the internet you know at least if you look up what other people are going through you think oh I’m not that bad or you know it can make life a bit more bearable because during winter months I’m more or less indoors.”</p>
EN39 Durme, Thérèse Van et al. - 2014	<p>The progressive generalization of electronic patient records within settings and the ICT federal platform of social security (eHealth) have allowed for shared information linking clinical files with built-in algorithms should support clinical decision-making.</p> <p>there is currently a lack of aggregated data for quality management purposes. Informants also stressed the lack of built-in algorithms for assessing the incompatibility between drug prescriptions.</p> <p>care providers in the study had heard about the ICT federal platform for the first time during our focus groups. (Social worker, 1st focus group) “It should be made possible for the patient to access his data, in order to claim the care or service provision to which he is entitled: preferential reimbursement rates, etc.”</p> <p>Professionals and patients expressed fear regarding the security and privacy of sensitive data</p> <p>reluctance to use shared electronic data files</p> <p>(GP, 3rd focus group, about electronic patient records) “This is very positive, but raises some ethical questions, because the patient might be unwilling to share his/her data. Important safety procedures should be set up.”</p>
EN42 Fairbrother, Peter et al. - 2013	<p>increased their knowledge of their condition</p> <p>reinforced their decisions to adjust treatment or seek professional advice , through practitioner monitoring, provided a sense of reassurance and support.</p>

	embraced enthusiastically
	telemonitoring would safeguard their health and support greater understanding of their COPD.
	easy to use
	access to clinical data about their condition which they considered beneficial in determining their state of health and recognizing illness. I
	prevent exacerbations and hospitalization.
	you can just take a reading and say; 'well, I do need a doctor or I do need to start these steroids.
	It gives me a lot more independence. I am not dependent on making the judgment myself. You're using measurements which normally wouldn't be available to me as a patient
	accessibility of the telemonitoring service
	reassurance
	watched over' by telemonitoring professionals
	". . . you still get the same attention [as 'usual care']. In fact, I'd say you get better because if [telemonitoring staff member] comes on the phone and she'll say "I think you're needing to speak to the doctor'
	. He accredits that to our service and the machine, and is petrified that when the trial ends that machine will be taken away from him, because it has become his life line. . . he's become dependent and believes he should be getting phone calls on a regular basis.
	I feel it reinforces a sick model for the patient. . . the patient would see themselves as very unwell on a daily basis because they're constantly focussing on their disease stat
EN44 Gagnon, et al - 2014	Even if we look at quality and safety, we do not look at them from the same viewpoint as the patient
	patients' viewpoints gave them a wider perspective and enabled them to obtain information that was not necessarily available otherwise
	Consideration of the patient's viewpoint could improve the appropriateness and applicability of recommendations
	providing more context
	usefulness
	patients could contribute to better acceptability, adoption and implementation
	improve the quality and efficiency of service
	to remain focused on the main beneficiaries of the decisions
	underscored the importance of patients being consulted in order to increase their autonomy and empower them
	the greater the potential impact of a technology on a patient's quality of life, the more relevant it was to involve them in assessing it.
	the type of technology cannot be considered alone. The specific evaluation questions and the kind of decision to be made are also factors to be considered in estimating the relevance of patient consultation
	Given that topics are varied, and even for us, it's always difficult, at the beginning of the research, to become knowledgeable about the technology
	the patient affected by the technology (or a close relative) should be involved in patient consultation.
	the need to select participants based on specific criteria, notably previous experience and qualities
	patient representative in the evaluation process must be a 'generalist' who does not represent a particular interest group or domain.
	several participants (principally in the focus groups) believed that the patient affected by the technology ('specialist') should also participate in the evaluation committee.
	experience was lacking among respondents. Hospital- based HTA units are still recent and many hospital managers and HTA producers felt unprepared for the integration of the patient's viewpoint:
	fear of slowing down the assessment proces

increasing its complexity
diverting the focus of the evaluation towards less essential aspects
additional time and costs (
Biases and industry lobbies associated with some patient groups also worried respondents from hospital
lack of knowledge and tools to help with the integration of the patient's perspective in HTA
additional work
to have targeted evaluation objective
on clearly defining the objectives of patient involvement
only involving patients if their contribution would have a real impact
to avoid creat- ing false expectations.
Time constraints,
complexity
heaviness of the approach
well-targeted consultation
objectives and specific dimensions to be analysed
Lack of financial and human resources in limited hospital budget
Complexity of the exercise in multicultural contexts
loss of control
Patient representatives particu- larly emphasized the medical and scientific jargon used by HTA committees
sufficient number of patient representatives on committee
careful selection with well-established criteria
preparation as well as clear information on their role
Organizing separate meetings with patient representatives
to maintain the same patient representatives in committees for a cou- ple of years.
EN45 Young, C. et al. - 2016
Data collected from the participant's own ACCHS, or from the local area, was often trusted more than data derived from more distal sources

Quotations - Barriers and facilitators in health literacy programmes

Table 37 - Critical barriers and facilitators reinterpreted

barriers to face-to-face groups (FTFGs); convenience of Computer mediated supporting groups (CMGs - online groups)	<ul style="list-style-type: none"> • I am not sure how you would do this, but education on the Internet would help (EN34)
COPING & PEERS'	<ul style="list-style-type: none"> • Women who lived in rural areas without easy access to FTFGs it took me so long to read the mail, that by the time it came for me to write, I was too tired to write(CO33) • Support groups that meet online are increasingly being used the online group allowed him to connect to people who he perceived to be similar to him, this participant did wish for the face-to-face contact that some (but not all) members of the group were able to experience.(EM10) • e-mail contact with persons who answered my questions, helped reduce my fear, and helped me come to terms with my diagnosis (...) Another survivor found reading blogs written by other patients who had experienced a procedure to be helpful and wrote, "I could better relate to their experience and it helped to know what to expect from a physical and emotional perspective." (CO27)
EMOTIONAL; SOCIAL MEDIA, ONLINE COMM	<ul style="list-style-type: none"> • Stories were shared about needing "emotional support" and turning to online communities. (CO27)

Quotations: Self-management

Cultural inadequacy	<ul style="list-style-type: none"> the Internet as their primary resource (CO08) technology including DVDs should be limited as many people might not have the hardware to use DVDs (EN01) foods mentioned in the internet are not available locally "Some of the things they suggest you eat is things that I haven't heard of", "You'll never find it (in this province)". (EN35)
FEELING IN CONTROL	<ul style="list-style-type: none"> ...tried to arm myself with enough information with the technology, with the right care providers so that I control the disease; the disease doesn't control me(CO31)
LACK OF CO-DESIGN	<ul style="list-style-type: none"> the "sleeping gym membership" phenomenon: registering for HealthSpace, accessing it once, then losing interest. (CO32) Some people in this subsample had no access to computers or the internet at home (CO32)
NOT TAILORED TO CUSTOMS	<ul style="list-style-type: none"> participants saw these technologies as serving other purposes in their lives (games, shopping, social net- working). (CO32)
WORKLOAD	<ul style="list-style-type: none"> relieve the workload of GPs (CO38)
DISADVANTAGE	<ul style="list-style-type: none"> Impersonal(CO38)
Depends on age and education	<ul style="list-style-type: none"> Not suitable for all patients (CO38)
ADVANTAGE	<ul style="list-style-type: none"> Increases patients' awareness of problems (CO38)