Tables

Table 1: Initial domains in the conceptual framework for the development of the LTCQ

Literature reviews of key domains	Stakeholder interviews [19]
1. Outcomes included in generic and disease-specific PROMs 2. Self-management 3. Coping 4. Empowerment 5. Burden of treatment 6. Stigma 7. Safety 8. Involvement in decision making 9. Information and health literacy 10. Ability to achieve goals 11. Social participation 12. Social support	1. Empowerment 2. Quality of Life or Impact of Illness and/or Treatment on Life 3. Patient-specific or Personalised Goals 4. Functioning (including social, physical and psychological) 5. Social Participation 6. Psychological wellbeing 7. Symptoms or Clinical Outcomes 8. Access to Services (includes Access to Information) 9. Joined up Nature of Services 10. Impact on Carers

Table 2: Topic guide for interviews

Primary care interviews	Schizophrenia interviews
1. Can you tell me a bit about yourself (e.g. living arrangements, day to day activities)? 2. What long-term conditions (physical and mental health) do you have? How long have you had these? 3. What aspects of your day to day life are affected by [condition/s]? 4. How has your health been recently? 5. Has living with [condition/s] changed over time? If so in what way/s? 6. Is there anything you're able to do to look after yourself and manage your health? 7. What help do you have in order to manage your health? 8. What are your main priorities in managing your [condition/s]? 9. How would you feel about being asked to complete a short questionnaire on your health every now and then, as part of your health care *(and social care)*? 10. Is there anything else that you would like to mention about the impact of your health on your day-to-day life?	1. Can you tell me a little about yourself? - 2. Can you tell me a bit about your current diagnosis? How long have you had this diagnosis? / Can you remember when you were first given this diagnosis? 3. Have you had any other diagnoses? If yes, can you tell me what they are/were? 4. Thinking about your health now… how do you feel that you are doing in general? 5. In what areas of your life do you feel you are doing well/not so well/having difficulties? 6. Currently, in which areas of your life /health do you feel it would be most important to see improvements? Are you currently receiving any form of treatment? What are your experiences of this treatment? What are the most important benefits or effects of the treatment(s)? 7. Can you tell me about when you have been unwell? Thinking back to this time period, what do you feel were the most important consequences or outcomes of the treatment you received? 8. Could we now talk about when you started to feel better/more stable? Thinking back to this time, what were the most important consequences or outcomes of the treatment you received? 9. Could we now talk about what happened when you started to feel a bit better/more stable? Thinking back to this time, what do you feel were the most important consequences or outcomes of the treatment you received? 10. Is there anything that we haven't covered that you feel is particularly important to mention in relation to our discussion?

Table 3: Characteristics of interview participants

		Primary care recruitment	Schizophrenia study
Number of interviews		42	6
Gender		22 men, 20 women	4 men, 2 women
Age range (years)		30 - 97	29-60s
Ethnicity		36 White British or Irish. Also one White European, one Egyptian, four South Asian	4 White British, 1 White European, 1 Black British
LTCs	*Single morbidity (n)*	18	5 with a type of schizophrenia and 1 with schizophrenia and anxiety NB. There may be other comorbidities but this was not asked for in these interviews
	Multi-morbidity (n)	24 (range 2-8 LTCs)	
	Participants per LTCs determining recruitment (n)	COPD (3), diabetes (14), IHD (6), cancer (5), depression (3), schizophrenia (0), stroke/TIA (5), IBD (4), MS (7), OA (10)	
	All other LTCs reported	Agoraphobia, asthma, bipolar disorder, borderline personality disorder, chronic kidney disease, chronic back pain / sciatica, chronic renal failure, chronic skin condition, diverticulitis, gout, hearing loss, heart failure, epilepsy, dyslexia, hypertension, hypothyroidism or other thyroid condition, neurofibromatosis Type 1, peripheral vascular disease, psoriatic arthritis, psychosis (drug-induced), spinal stenosis and visual loss	
Social care use		7 with some form of social care experience	Participants were not asked about use of social care

Table 4: The three main overarching concepts with their themes (bold) and sub-themes (italics) identified within the interviews

Impact of the LTC(s)	Experience of services and support	Self-care

- **Achieving personal goals**
- **Health status**
- **Impact on day-to-day activities**
- **Impact on emotional or mental well-being**
- **Impact on family or carer**
- **(In)dependence**
  o *Independence*
  o *Dependence/ sense of being a burden*
- **Loneliness**
- **Physical activity**
- **Roles and responsibilities**
- **Safe environment**
- **Social participation and involvement**
- **Stigma**
  o *Self-perception*
  o *Social stigma*
- **Suitability of home**
- **Temporal awareness of LTC(s)**
- **Worry about staying well in the future**
	- **Burden of care**
	  o *Burden of services*
	  o *Burden of treatment*
	- **Experiences of services**
	  o *Sense of being (un)supported by services*
	  o *Dignity*
	  o *Level of expertise of services*
	  o *Pressure on services*
	  o *Use of private health care*
	- **Involvement in health decisions**
	- **Social Support**
		- **Coping with LTC(s)**
		  o *Through planning or adjusting to LTC(s)*
		  o *Re-prioritisation in light of LTC(s)*
		- **Empowerment**
		- **Self-management in relation to LTC(s)**
		  o *Confidence to self-manage*
		  o *Desire to self-manage*
		  o *Knowledge and /or information to manage LTC(s)*
		  o *Skills to manage LTC(s)*

Table 5: Theme, sub-themes, n and rank of interviews endorsing theme

Theme	Sub-theme	Schizophrenia (n=6)	LTC (n=42)	Total (n=48)	Rank
Experiences of services	**Sense of being (un)supported by services**	**6**	**41**	**47**	**1**
Impact on day-to-day activities		**5**	**41**	**46**	**2**
Social support		**6**	**38**	**44**	**3**
Social participation and involvement		**6**	**37**	**43**	**4**
Impact on emotional or mental wellbeing		**6**	**36**	**42**	**5**
Coping with LTC(s)		**5**	**35**	**40**	**6**
Self-management	**Knowledge and/or information to manage LTC(s)**	**4**	**36**	**40**	**6**
Burden of care	**Treatment burden**	**6**	**32**	**38**	**8**
Achieving personal goals		**6**	**30**	**36**	**9**
Self-management	Skills to manage LTC(s)	3	32	35	10
Empowerment - a sense of control over one's daily life		**5**	**28**	**33**	**11**
Self-management	Desire to self-manage	2	30	32	12
Physical activity		**2**	**28**	**30**	**13**
Self-management	**Confidence to manage LTC(s)**	**3**	**26**	**29**	**14**
Burden of care	**Service burden**	**3**	**25**	**28**	**15**
Stigma	**Social stigma**	**5**	**22**	**27**	**16**
Roles and responsibility		**2**	**25**	**27**	**16**
(In)dependence	Independence	2	25	27	16
Stigma	Self-perception	4	19	23	19
Health status ratings		2	21	23	19
Experience of services	Level of expertise from services	3	19	22	21
Coping with LTC(s)	Coping through planning or adjusting way of living	3	18	21	22
Worry about staying well in future		2	17	19	23
Experience of services	**Dignity (how you are treated by services)**	**1**	**17**	**18**	**24**
Safe environment		**3**	**15**	**18**	**24**
(In)dependence	**Dependency or being a burden**	**1**	**16**	**17**	**26**
Involvement in health decisions		4	13	17	26
Impact on family or carer		2	13	15	28
Suitability of home		**0**	**15**	**15**	**28**
Self-management (esp. relating to LTC(s))		1	13	14	30
Temporal awareness of LTC(s)		1	13	14	30
Loneliness		**0**	**12**	**12**	**32**
Experience of services	Services as pressured - sense of responsibility	2	9	11	33
Experience of services	Using private healthcare - reasons	0	11	11	33
Coping with LTC(s)	Re-prioritisation in light of LTC(s)	2	8	10	35

NB. (Themes/sub-themes in bold were considered for item development)

Table 6: LTCQ dimensions, qualitative themes (and ranks) and illustrative quotes

Impact of LTCs		
LTCQ dimensions	**Definition (coding framework)**	**Examples from the qualitative interviews**
Achieving personal goals	Any personal goals (- i.e. something participants talk about valuing or wishing they could do) and how LTC(s) impact on ability to achieve personal goals or how goals have changed due to the LTC(s).	'...The arthritis, yes, it does, at the moment, with the damp weather and things. I'm waiting for a knee replacement and my knee is giving me so much... restricting my movement quite a bit, I'm in quite a bit of agony and it restricts my movement, which is annoying me, because I'm not someone who can sit for long periods doing nothing, but this is forcing me to do that, which I really am not enjoying at all…' *68 year-old woman with diabetes and psoriatic arthritis* '… I want to be able to carry on walking the dogs properly and we have – believe it not – there's a swimming pool out there, I'd like to be able to keep swimming, because that's such good exercise…'*54-year old woman with MS*
Dependency and being a burden	Feelings of being too dependent on others for basic or other needs, e.g. feeling like	'… Pretty much I look after myself, I do all my own cooking and stuff, so. I manage the diabetes, nobody else gets involved with that, I do all the injections and put all my tablets out, and so I do all that myself…' *59 year-old man with diabetes*

	a burden, unhappiness about having to rely on others, future fears of dependency.	'… It's just been the same, I don't think anything's really changed except for the fact that as time goes by I seem to get less and less independent… I've been used to being independent and losing that independence has been the hardest thing in the world…' *64 year-old woman with MS, arthritis, stroke and problems with vision* '… As long as I live I want to be fairly healthy for them [family], so I'm not a burden…' *76 year-old woman with COPD, asthma, OA, diverticulitis and depression* '… we have done holidays with friends, and you just feel very conscious that if I'm there, I'm restricting what they can all do, it's not just me, it affects everybody else… you know we're aware that all the others are thinking that they'd like to go off and see this thing, or do that thing, and you tend to really hold back and try and persuade "just go, don't worry about us going, you do it", you know, and I feel hard done by but I don't want to put the extra burden on other people…' *55 year-old woman with MS*
Impact of LTC(s)	Impact LTC(s) have on ability to complete day-to-day activities (like cooking, cleaning, work, self-care,	'… [it] made me think 'if I don't take my medicines this time, I'm going to have a newborn, and a 5 year old at home, and I'm going to be in hospital, and there's no one to take care of them", do you know what I mean, so since then, since that one attack during pregnancy, I've been taking my remission medication like it's a religion…' *33-year old woman with IBD*

	looking after family/pets) and impact on emotional health and mental state, including LTCs causing anxiety/worry; feeling depressed as a result of LTCs; difficulties concentrating etc.	*(ulcerative colitis)* '… I do arrow words and crosswords just to keep my brain going, because I've got this stupid memory that drives me absolutely silly, and I keep thinking 'well I don't know, as long as do things like that, it'll keep my brain moving', and I do tend to do a lot of those, it makes me relax to be quite honest, because I used to be really, really fit, really, really busy, you know, I never had time to sit around or anything, but now I'm stuck because I've got all this time and I don't really want it, so I've got to fill it in or else I get depressed…'*64 year-old woman with COPD, stroke, arthritis, agoraphobia, depression, IHD, gout and stenosis of the spine* '… perhaps when I was at university, various things where I was convinced that I really wasn't, you know, I was the lowest of the low, and I had absolutely no self-esteem whatsoever and I couldn't believe it if, you know, a bloke chatted me up, I thought he was only after my good looking friend, or whatever, and times when I've, you know, just been convinced that people have only sort of put up with having me around for one reason or another, rather than actually being genuine friends and I look back on that and think "Well, yeah, that's... you were depressed at that point"…' *44-year old woman with depression and osteoarthritis*

Loneliness	Perceptions of whether social contact is adequate or potential loneliness as a result of LTC(s), worries about loneliness and the impact of LTCs on social contact and loneliness.	'…I'm very lucky I say in having [neighbour] next door to me, that's because there is nobody else up here that could be the same as him next door, you know where I can go in, have a little chat, discuss what's in the paper and that sort of thing, and that believe me is a big thing when you're stuck up here all day long…' *97 year-old woman with OA, hypertension, hearing loss, chronic back pain, knee replacement and sciatica* '…It's quite funny really. And if it wasn't for my son visiting twice a day, and my dog and my cat, there'd be nothing in my life really, you'd just be sitting here looking out the window or watching the television and that'd be it...'*64 year old woman with MS, arthritis, stroke and problems with vision* '… I must admit I am quite [um] content with my own company when I'm not doing anything…. But I do like company from time to time…' *45 year-old man with schizophrenia and anxiety*
Physical activity	Impact of LTC(s) on physical activity levels. This might overlap with impact on day-to day-activities, as these often	'… I have a friend who lives very high up and there are no lifts, there's eighty four steps and it's just too much for me, I am out of breath at the top of that, steep hills are a bit of a problem…' *76 year-old woman with COPD, asthma, OA, diverticulitis and depression* '… I used to walk miles, I ended up walking with the aid of a stick, but before that I could

	require physical activity, but additionally includes exercise as a physical activity undertaken for health or leisure purposes.	walk miles. I think it sort of descended on me suddenly and I don't know why and I couldn't walk without the aid of a stick or a frame and that reduced my activity right down…' *87 year-old man with cancer and chronic skin condition* '… cos you feel like you want to do some exercise, just to keep some sort of fitness, but because of the fatigue side of things, it just took over too much of life, because I would do the gym, then come home, be completely wiped out, couldn't do anything … so [gym] three times, [a week] I think the MS physio, I think she said she thought that was too much, so I've cut it down now to once a week, and that's only about half an hour, which half of me thinks, is there any point me doing that, cos it's such a tiny thing, I sort of half feel it's not worth doing…' *55 year-old woman with MS*
Roles and responsibilities	Impact of LTC(s) on a person's ability to undertake valued social roles and where LTC(s) affects their ability to take on or fulfil responsibilities e.g. parenting, family duties, work,	'…I didn't want to leave work. But since 2007 I've just not been well, one thing after another, and I just had to give up my job which wasn't great for me, because I loved my job…Loved it, really loved it, but then I started to get sick this, that and the other and in the end it wasn't fair on them and it wasn't fair on me, so my husband's struggling a bit, so I thought no this has got to stop, so I was of retirement age anyway, well nearly, so you know I just had to bite the bullet as you do…' *64 year-old woman with COPD, stroke,*

	or community responsibilities	*arthritis, agoraphobia, depression, IHD, gout and stenosis of the spine* '… I have to take the wife to do the shopping, I can't go in with her because it's too far to walk you know, so I have to sit in the car and I can't take the dogs round the park anymore, that upsets me quite a bit…' *70 year-old man with diabetes, OA, stroke, angina, hypertension and cancer*
Safe environment	The extent to which people feel safe or unsafe in relation to inside and outside their home, in particular when this is health-related e.g. falls in the home. From a social services perspective, people may also feel unsafe for other reasons, e.g. fear of abuse, crime etc.	'… I've slowly but surely got worse over the years, my walking is a joke, I can't... I do go out, but I'm very nervous the whole time because this foot goes out to the side and I've got no muscles to keep it over… I've not got the freedom I used to have, because I'm scared to go out on my own now. I have to go out, thank goodness, because I've got [DOG] to walk in the mornings, and my son comes in, takes him out at night for a long run, but I've found I need to keep my head up and look where I want to go, because if I look down or look around, I can get dizzy and lose where I am…' *64 year old woman with MS, arthritis, stroke and problems with vision* '…I had had a fall down these three steps and I couldn't get to my phone, I had to loaf around on the floor all night. I got to the fridge, I got a pint of milk out of there and I waited for the paperboy to come in the morning…' *88 year-old man with diabetes, COPD, OA and*

		hypertension '… [it] depends where you live, doesn't it. I feel quite safe round here, I know it's a bad area but it's what I'm used to, I would feel less safe in somewhere like somewhere posh because of people's attitudes…' *49-year old woman with diabetes, borderline personality disorder and sciatica*
Social participation	Social activities and any social involvement that people value that are negatively or positively affected by LTC(s), e.g. family-related activities, activities with friends, and voluntary activities or work-related activities that are valued for the social aspect.	'… I guess I could be a bit more sociable sometimes but half the times I don't know if I can really…if I'm really in the mood to do anything… ' *29-year old woman with paranoid schizophrenia* '… I also meet up with a group of people that have MS. They meet up once a month in the evening, go have dinner … [HUSBAND] said he'd rather stick his head in the sand, pretend it wasn't happening. Whereas I just wanted to just meet other people, and my sister said, "trust you to make it a social occasion" [LAUGHS]…'*45 year-old woman with MS* '…the people I know and socialise with, know that I have a limitation, and they take that into consideration. Sometimes it's forgotten, but I'll do things at my own pace. We go out once a month, a group of lads from the village here, go out on a beer and curry night, into… We take in our local pub, then we have a coach take us into [CITY] … there is a bit of

		walking once the coach has dropped us off. There was one particular evening, where the walk was a bit further and I was struggling. So we got a taxi, it was called a police car [LAUGHS] took me to the curry house. It took a bit of explaining to get it done but they did get it done, because I can take that light heartedly, but I would have got there anyway, but it would have taken just another 10/15 minutes for me to get there, I wouldn't have tried to keep up with people, that's the key. If we're out walking, I will do it at my pace, and if I need to rest, I'll rest, therefore I won't let it get too uncomfortable, I can feel it coming on and just slow down, take a rest, as I need to…' *59-year old man with diabetes, arthritis and circulatory problems*
Stigma	Negative judgements or worries about negative judgements upon a person by virtue of LTCs including internal (people view themselves less positively or negatively) and external stigma (perceived negatively	'… Everybody started talking about me saying rumours and saying I was thick and you know sort of saying I was bent and all that sort of thing; and then I got a complex about myself …' *HL03 45 year-old man with schizophrenia and anxiety* '… there's things sort of like when you have questionnaires to do with mortgage and whatever, life insurance, and when you're talking to a financial advisor, they go "Oh, yeah, we've just got the quick questionnaire to do, and you know, obviously you've never suffered from this, this, this and this," and you say "Well, actually yeah, I'm on anti-depressants and probably will be for the rest of my life" and you can see this sort of "Oh,

	by other people).	you poor thing" and "Oh crumbs, what do I say now?" kind of look on people's faces. But again, I've got less sensitive about that and as years go by, you always think, well, yeah it's just part of me that doesn't quite work properly…' *44 year-old woman with depression and osteoarthritis* … I don't feel that stigma, I think 'well that's your problem if you think you know that I'm different' … Just to give you an anecdote, when I was first diagnosed with MS, I went to ... announce it to my parents, and when I said, 'I've been diagnosed with MS' and explained what it meant, my father's reaction was, "don't you find that very embarrassing?" And I thought 'no I don't', and I've never found it embarrassing, I don't feel embarrassed. You know I'm a man, I have sexual problems, do I find that embarrassing? No, it's just a fact…' *67-year old male with MS*
Suitability of home	Any problems with accommodation from a health-related perspective including any solutions that helped alleviate the problems such as walking frames, walk-in	'…We got an extra bannister, a wall bannister, going up the stair, and I tend to hold onto both when I'm going up and down, I feel going up and down is quite good for me…' *65 year-old woman with MS* '…can't go out walking with the dogs because of my legs, and there's several things I can't do but it's a struggle sometimes to get upstairs, I've had one or two accidents because I

	showers etc. Includes support by social services.	couldn't make it upstairs quick enough [LAUGHS], a bit silly, but you don't really want to know about that do you…' *70 year-old man with diabetes, OA, stroke, angina, hypertension and cancer* '…the house, I mean I don't think it's too bad, it's clean, a bit cluttered I suppose with gadgets for the animals. I want to be comfortable, I'm stuck in a lot, I want to be comfortable, and I can't be any more comfortable I don't think, and this is my cocoon this house, cos I mean there's some days I just don't want to go out of it…' *64 year-old woman with COPD, stroke, arthritis, agoraphobia, depression, IHD, gout and stenosis of the spine*
		Experiences of services and support
LTCQ dimensions	**Definition (coding framework)**	**Examples from the qualitative interviews**
Burden of treatment and services	Burden of treatment is whether treatment(s) creates burden or difficulties, or whether treatment(s) are easy and clear to manage.	'… I'm seen bi-monthly by the renal team at [hospital] so I'm in hospital as an outpatient on average once a month because I go in, twice every two months if you see what I mean, I'll go in once to have some blood tests and then back again a week or so later for a clinic, so that's twelve times a year. So I'm in hospital very regularly, go to my GP as needed, very regular blood tests, administration and medication that I can't give myself, I'm on a

	Treatment(s) includes any interventions (e.g. dietary, exercise or social services) or medications. Service burden refers to whether services create difficulties (e.g. high frequency of consultations, expense, difficulties with access). This is specific to the process of using services and relates to use of health, social care and community services.	range of medication that supports both how I feel but also to keep my kidney function as good as possible, so I have to inject myself weekly with a hormone called EPO, which you probably know about, on top of the tablets, then they give me injections of the iron when needed, that's about it really…' *35-year old male with IBD and chronic renal failure* '… I don't go to the doctors often to be honest, but I have appointments up the [HOSPITAL] for the diabetes, every 6 months, and I go to the heart clinic once a year, that's not too bad, but it can be annoying when you have to go to the doctors, but it's not too bad…' *70-year old man with diabetes, stroke, IHD, gout and chronic back pain* '…It's just the side-effects of it and it's a bit, it's annoying because I have actually…you know I have asked whether my medication can be changed to something completely different but they're…their feeling is that they don't, they think the [um], they don't think that's a very good idea. They don't think the side-effects of that are severe enough for me to change…' *29 year-old woman with paranoid schizophrenia*
Dignity	Dignity experienced within health and social care and includes how respected and	'… the worst thing for me was after I had my operation, this was another bug bear of mine, I was told beforehand that there were cancerous nodes and that's why they had to be removed … from the day I was diagnosed, the doctor sent to me to the specialist, I was like

	valued people feel when accessing services and whether they feel treated as an individual (or not) by services.	a hamster on a wheel, I couldn't get off, you know it's going to happen but you can't stop it [LAUGHS] and after the operation was done this woman came in and she pulled the curtains round me and she said "by the way, you're diagnosed with cancer", and she walked out and she left me with that, and for me it was just a brick that she had hit me with, and I was so angry, I really was, I saw red and afterwards I just cried and cried and cried, and when somebody asked me "why?" and I tried to tell them, they went "what?" I said "yes". I sincerely hope and trust that they take them to task about it, because that's an awful thing to do to anybody…' *70 year-old female with diabetes and thyroid problems* '…there was a time a little while ago when I was starting to feel really quite down by it, and I just had a great chat with my GP about it, and about what to do and you know, and possible therapy options and what we could do if things got worse, which they didn't, yeah they're very, very pleasant people working in an imperfect system, but they are excellent in that they understand….I think they understand very well the nature of chronic conditions…'*35 year old man with IBD and chronic renal failure*
Support	Any support people with LTC(s) receive or do not receive, including help by	'… I get tired … I'm trying to take it easier, cos I like working hard and doing it all myself [LAUGHS] but I have to let others do stuff for me…' *45 year-old female with MS*

	health and social services and support by significant others such as family, friends, neighbours, work colleagues.	'… you come away from somewhere like the doctor or a consultant and you think what was the flaming point of all that, he doesn't... he's... they're only interested in what is physically wrong, they don't want to probe what impact it's had on you…' *64 year old woman with MS, arthritis, stroke and problems with vision* '… There's some people who know about the chinks in my armour and that's fine and strangely enough I was with one yesterday afternoon, who I hadn't seen for a while, because we used to sit next to each other when we worked [together]… She knew, just by my mood, if there was something... if my blood sugars were dropping or if there was something wrong and she would say "Have you checked your blood sugar?" and I actually said to her yesterday how I miss that so much, but she just knew by how I was what was going on, but, you know, we don't work together anymore and it was funny, at the time, I kept saying "Oh, [name] don't fuss", but I realise I did really appreciate that a lot…'*58 year-old woman with diabetes and asthma*
Self-care		
LTCQ dimensions	**Definition (coding framework)**	**Examples from the qualitative interviews**

Coping	Any tactics or methods used to cope with LTC(s) such as accepting the LTC(s) or finding different ways of doing things. It can include problems or difficulties that lead to people not coping with LTC(s). and emotional responses to LTC(s), e.g. feeling overwhelmed or frustrated.	'… do I regret the things I can't do? No, I just can't do them, so you know, even if I hadn't had MS, I would never have been able to climb mountains. Do I regret I can't climb mountains? No, I just can't do them, so I apply that to other things, you know I'm getting older, I've lost all my youth, do I regret losing all of my youth? No, not really, things just move on and I cope with what I've got…' *33-year old woman with IBD (ulcerative colitis)* '…I stay on these tablets I'm on, they tried me to go back on some others that are not so potent, but every time I take them I get the diarrhoea, so I had to stop taking them… you do live in a little bit of a fear of 'you might go to the toilet any time of the day', and I don't wear pads very often now, I chance it and hope for the best, but I do wear them occasionally if I'm going to go on a long journey, like I went on holiday, and yes I wore when, when I was on the plane, well you think, 'I could get stuck on the plane'… I always carry pads and cleaning stuff with me, all the time, because I never know when I might just suddenly go, and I need to clean myself up and I have been caught out when I've been on walks, along the sea coast and things, I've got caught out and had to find a loo, and change my knickers or chuck my knickers away, and put new ones on, catches you out, you know. I live with it, I don't say it's good, but I live with it at the moment …'*66 year-old woman with IBD (ulcerative colitis) and cancer*

Empowerment / sense of control	Feeling empowered and in control and the process of being enabled to be in control of life through support and help by treatments, services and other people	'… I'm in control of everything, completely, not just my life, a lot of the people around me will come to me for advice and steer them…' *59-year old man with type 2 diabetes* '…I mean the more dialogue there is about long-term illnesses, I would have thought the better. The more real dialogue, well for me it's important, and whether it is for other people, but for me it's the importance of as I've said already, of being engaged in it, and feeling that it's under my control, and that I have a big say in what's done to me…' *69-year old man with IHD*
Information and knowledge	The resources people have or need to understand and manage their LTC(s).	'… access to better information. I think that's something the NHS tends to neglect. The GPs tend to have information that they impart, when they want to impart to you when you're, you know, in your 10 minute consultation you get [very little] information during that time. Sometimes, they give you some articles they get off the web, they print out for you. But generally speaking that sort of level of information is fine, but I tend to want more information…' *71 year-old man with diabetes and cancer* '… I think a lot of people find it difficult to find out information from social services, about what they're entitled to, rather than what they can get, but what they are entitled to, I wouldn't know, if I was entitled to any help or not, not now but in the future, people don't

		know, a lot of people don't know…'*70-year old man with type 2 diabetes, stroke, IHD, gout and chronic back pain* '… you've got a colitis [society] that you can join, I think it's a booklet they send you, every so often, and you can read about other people, or you can go to meetings and meet people, I'm not saying you do, but you can, there are obviously associations around, where you can go and talk about your problems, or what's going on in your life, and you get these books, and they tell you about it, and the hospital gives you 3 or 4 booklets when you come out, that tells you sort of about it, and tries to describe what's it like and what it's not like…' *66 year-old woman with IBD (ulcerative colitis) and cancer*
Confidence to manage LTC(s)	Confidence or a lack of confidence (could be anxiety or feeling overwhelmed or confused) to manage LTC(s) and/or any treatments and/or any medications in relation to their LTC(s)	'…it's really down to the person at the end of the day. You can be talking to goodness knows how many people about how you're feeling and this, that and the other, but really and truly if you're not really ready to make a change or you're not well enough to make a change or whatever, nothing…it's not going to make no difference…' *29 year-old woman with paranoid schizophrenia* '... I increased my walking and sometimes I think cut down on the sweets, cut down on the sugar and things like that, you know. But apart from that, sometime I find that I need a bit

		of sugar, my body will ask, and then I say "well, why did I do that" and then when you do it, then you find that and you know that your level was going low, or whatever, you become a doctor for yourself…' *75 year-old man with IHD* '… I believe I manage my diabetes quite well. Hence why I'm not having constant hypos and I'm not having, I try and watch out for it going too high. I don't test myself every 5 minutes, but I've learnt how my body feels, and I can tell when things are not quite right…' *59 year-old man with diabetes, arthritis and circulatory problems*