Supplementary File 4

Findings from interviews with stakeholders

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In this supplementary file, we present the methods and findings from interviews with stakeholders in health care in England from both national level and regional levels (the latter in integrated care systems (ICSs) or integrated care boards (ICBs)). The interviews were designed to address two of the overarching study's research questions:

- **RQ1**: To what extent does it appear that the needs of people with multiple long-term conditions are driving integration and the approach to integration being taken by NHS Integrated Care Systems (ICSs) and the organisations within them?
- **RQ2**: What might a system of service innovation that prioritised people with multiple long-term conditions look like and how could this be achieved?

Methods

A semi-structured interview guide was developed to help guide the interviews. Questions were related to understanding the participant's perspective on specific care needs that people with multiple long-term conditions may have, innovations put in place to address those needs, and the role of ICBs/ICSs in addressing those needs. Questions also related to mental health needs of people living with multiple long-term conditions and measurement of their experience of care. General questions relating to known examples of good practice and elements of a healthcare system that prioritised care for people with multiple long-term conditions were also asked.

The sampling approach included both convenience and snowball sampling. An initial list of potential participants was generated by the research team: 21 total, consisting of 12 with responsibilities at a national level in England and 9 at a sub-national level. Participants were also asked during recruitment and during interviews to identify additional individuals that the research team should approach.

All individuals who agreed to participate were emailed with the participant information sheet, given the opportunity to ask questions, and were asked to review and sign the consent form. Interviews were conducted between 21 November 2022 and 18 January 2023 by three researchers with experience conducting interviews (SS, FW, JSm) via videoconferencing software (Microsoft Teams). Interviews lasted between 26 – 57 minutes. All but two interviews were recorded using the recording and transcription software within Microsoft Teams, and the recordings were used to help to summarise responses to questions in the interview topic guide for each participant. For the two interviews that were not recorded (due to failure of the technology) the interviewer took extensive notes during the interview and used those to summarise in line with the other interviews. Field notes and summaries of responses under each question were collated and analysed by the interviewers and the rest of the research team in collective discussion across both national and sub-national participants. In the following section, we report the main themes arising from the interviews.

Findings

Of the initial list of 21 potential interview participants, 12 agreed to participate. From suggestions by the interview participants, 11 additional people were invited to participate in interviews. In total, 18 interviews were conducted with 19 interviewees (9 national, 10 sub-national). The roles they were performing at the time of the interview are summarised in Table S4.1.

Table S4.1. Roles of interviewees

National (n = 9)	Sub-national (n = 10)
Academic GP (n=2)	GP with relevant leadership role at trust or ICB/ICS level (n=5)
NHS England manager for relevant programmes (n=2)	Senior nurse with relevant leadership role at trust or ICB/ICS level trust (n=1)
Leadership role at patient charity (n=2)	Specialist consultant with leadership role at trust or at ICB/ICS level (n=2)
Senior leadership role for ICB/ICS (n=2)	GP with relevant leadership role at Primary Care Network level (n=2)
Clinician with senior leadership role within an Academic Health Science Network (n=1)	

Below we present the main themes arising from the interviews. The findings are organised by questions or set of questions asked as relating to the semi-structed interview guide.

Care needs of people with multiple long-term conditions that service innovation most needs to address

Some participants from both national and sub-national levels commented that people with multiple long-term conditions are a large proportion of patients and that the needs of this group were heterogenous and sometimes complex, often including social care needs that impact medical/clinical needs (S2a, S3, S7, S8, N1, N3). One national interviewee commented that because of the large population of people with multiple long-term conditions and the diverse needs of each person, that there is not one care pathway that would be appropriate for all, and added that in some cases there is no need for a special care pathway:

> *"for most people, multimorbidity it's fine as it is. You don't need to do anything different […] You could have loads of conditions, but actually be managing just fine. And you don't need a different approach to care." (N1)*

However, there were eight broad categories that were identified as particular care needs of people with multiple long-term conditions that service innovation most needs to address, and these are described in turn below:

- Holistic care
- Integrated care
- Coordination of care (for some people)
- Continuity of care
- Self-management / self-care
- Patient-centred care
- Access to care and medications
- Medication concordance and poly pharmacy

Holistic care

Ensuring holistic care was the most commonly mentioned category among interviewees as a need of people living with multiple long-term conditions that service innovation most needs to address (S1, S3, S4, S5, S7, S8, N3, N4, N6, N7, N8). This involves *"seeing the patient as an individual with a number of diseases, not seeing the patient a number of times with individual diseases" (S3)* and includes consideration of people's emotional and social care, as well as health care, needs (S5, S7, S8, N3, N9).

There also needs to be less distinction between mental health and physical health needs, as they are often intertwined (S4, S5, N4, N9). It was suggested that *"a holistic approach that blends the physical and psychological with daily living and functioning and social well-being" (N7)* was needed for people with multiple long-term conditions. Such an approach would consider social care needs and acknowledgement that patients may at times prioritise them over clinical concern. For instance problems relating to housing, which is impacting their health, may be a greater priority for the patient than their health (N6).

The complexity of a holistic multiple long-term conditions consultation requires a longer appointment time, especially in interacting conditions (S6, S7, S8). However, another interviewee commented that whilst holistic care is the goal in primary care, it is often difficult to achieve given the short consultations within the contractual and other frameworks in which they operate (N8). One sub-national interviewee commented that the limited time allowed for appointments limits the ability of the patient to be truly involved in the decision making around their care because clinicians do not have time to help them understand the trade-offs that need to be considered due to having multiple long-term conditions that potentially interact (S8).

Relatedly, ensuring that care provided was patient-centred was mentioned by both national and sub-national interviewees (S3, S6, S8, N1, N3, N4, N6). Interviewees felt it was essential to consider what is important to the patient (which may differ from what the clinician/system thinks is important), how their conditions impact them, and also what the treatment burden might be (N1, N4, N8, S3, S8). Similarly, at any particular time the dominance of one health condition over another may differ in terms of priority for patients compared with clinicians (S8).

Integrated care

Holistic care links to problems with care integration and care being *"quite disjointed" (N3)* among service providers. Services are designed and operate in silos (N4) and are single condition focused (N8, S9), so that patients are seen by different clinicians for different conditions in different appointment slots. It was suggested that a more integrated approach whereby patients have one appointment addressing all conditions, considering the potential interactions or the same underlying mechanisms/causes, may be more beneficial (N6). This could even begin before the appointment; for example, many conditions are monitored using blood tests, and rather than a patient needing multiple blood tests, one could be done to test for all required markers (N7). *"Making every contact count"* was mentioned by a sub-national interviewee (S1), meaning that existing appointments could also incorporate checks for other conditions in both primary care (e.g. if an appointment is for a mental health condition, a diabetes check could be done at the same time) and secondary care (e.g. pre-surgery checks could also include a cardiovascular screening update if needed).

Coordination of care (for some people)

The coordination of care was also commonly mentioned among interviewees as a need of people living with multiple long-term conditions that service innovation most needs to address (S1, S2a, S6, N1, N2, N3, N7, N8, N9). This included care coordination across different health care sectors, particularly across primary and secondary care, but also across wider systems like social care. One sub-national interviewee noted that in some instances utilisation of multiple clinicians and services is most appropriate to ensure the quality of care is not compromised (S3). However, siloed systems increase the demands imposed on the patients (administrative burden, time) and may represent inefficient use of limited resources (N4, S3). Fragmentation of systems and poor communication between systems mean that patients are more likely to get 'lost' in gaps (N3). Whilst some patients with multiple long-term conditions are able to be their own care coordinators, others with more complex multiple long-term conditions can *"struggle to juggle that complexity" (S1)*. The administrative burden on patients was highlighted by two national interviewees (N3, N9) as an aspect that patients may struggle with in relation to their care that may mean they require care coordination: *"it can feel like you almost have to become your own secretary […] Just the sheer amount of bureaucracy" (N3).*

A national interviewee (N1) commented that only a clinician would be able to identify those who might need care coordination because the data available are not able to identify this. For example, two patients may appear, based on the data, to be identical but one may need care coordination and the other not. Another national interviewee (N8) mentioned that people want signposting and regular communication, which may be sufficient for many people with multiple long-term conditions, rather than requiring someone to be a formal care coordinator.

Continuity of care

Continuity of care was mentioned by some participants, mostly in relation to General Practice and by participants who were practising GPs (S4, S5, S6, S8, S9, N2, N5). Care continuity was more important for people with multiple long-term conditions with complex needs, compared to people with multiple long-term conditions that are well-controlled and well-managed or people without long-term conditions who seek help for acute issues. Some participants mentioned that General Practice has moved away from continuity and is now focused on *"on the day access"* (S8). Where continuity of care is not possible, one national interviewee (N2) mentioned handovers between clinicians and integrated care pathways may be helpful so that the patient is not having to 'repeat their story' to each new clinician.

Self-management / self-care

Encouraging patient activation, whereby patients take greater responsibility for their own care, was mentioned by some participants (S2a, S2b, S3, N2, N5, N9). Traditionally the healthcare system may operate paternalistically, taking responsibility for care away from patients. As this can increase the burden on the service, it was felt that encouraging patient activation would be helpful in managing resources from an operational perspective. It was felt by at least one interviewee that empowering patients in self-management is suitable for a large proportion of people with multiple long-term conditions (N5).

Access to care and medications

Being able to access care and medications in a timely manner, especially following the COVID-19 pandemic, was mentioned by some interviewees (S2a, S2b, S4, S5, N2, N6). Many routine health monitoring checks for patients with multiple long-term conditions were postponed or cancelled due to their non-urgent nature during the COVID-19 pandemic, when services were under extreme pressure and many of the clinical staff redeployed (S2b). This has led to backlogs and for many patients their conditions have deteriorated, leading to unexpected hospital attendances/admissions, or more complex care needs (S2a).

The geographical location of where patients live and where the services are was mentioned as a challenge for people with multiple long-term conditions (N2), especially in rural locations (S4), but could also be applied to all patients.

Depending on the conditions, it may be that traditional methods to access to care (e.g. booking appointments with a GP via telephone or online system) are not appropriate for all patients, and so the accessibility of care for people with multiple long-term conditions can be a challenge (N6). For example, some patients with learning disabilities or serious mental health conditions may struggle with anxiety around booking appointments, meaning they do not book in and their other long-term conditions go untreated and unmonitored.

Medication concordance, continuity and polypharmacy

Lastly, a few sub-national interviewees, all practising GPs, mentioned needs around medication concordance and polypharmacy for people with multiple long-term conditions (S2a, S3, S4, S7). This links to challenges around concordance, helping the patient understand why they are taking a medicine, deprescribing, and interactions and contraindication between medicines and conditions. One interviewee mentioned that continuity of medication can be an issue for people with multiple long-term conditions if they are admitted to hospital, sometimes due to a lack of information sharing between primary and secondary care, or simply due to the change in routine (S4).

Mental health needs of people with multiple long-term conditions

One of the main challenges is that mental and physical health are often treated separately, and whilst coordination between the two is better than it was, improvements still need to be made which includes workforce skills, service design thinking, and changes in funding structures to enable a joined up service (N1, N4, N9, S3, S8): *"I think I mean there is a desire on both sides to do more together, but there's no real mechanism" (N1).*

Some GPs may treat physical and mental health needs simultaneously (e.g. during annual reviews); but the limited appointment time often means that interactions are task oriented and tend to focus more on one or other type of need rather than both together (N1, N5). Other interviewees believed that mental health needs were not particularly well considered in people with multiple long-term conditions (N3, S9). For example, one interviewee (N9) mentioned there being an often fatalistic response from healthcare providers to people with multiple long-term conditions with a mental health related concern, rather than a preventive, proactive approach to offer mental health support.

Specific services that were mentioned that target mental health in people with multiple long-term conditions included:

- ‘Improving access to psychological therapies (IAPT)’ programmes for people with long-term conditions (N5, N7, S7)
- Drop-in clinics and check-ups for people with learning disabilities or severe mental illness for multiple long-term conditions check-ups (N6, S2a, S4)
- Self-help resources – available to all patients (S2a)
- Mental health specialists embedded in physical health teams (e.g. psychologists) and physical health specialists embedded in mental health services (S7)

Existing innovations to address the needs of people with multiple long-term conditions

Some interviewees at a national level were unable to recall any service innovations that were specifically intended for people with multiple long-term conditions (N1, N2, N4, N8):

> *“I could honestly say I know of virtually no in the service innovations for people with multimorbidity, but I do know of lots of service innovations for older people or people in later life which are effectively multimorbidity interventions” (N1)*
>
> *“So at the moment you know we treat long-term conditions individually, we don't treat them collectively […], you know to try and identify a single innovation which would help the broad umbrella of things like long-term conditions, it's really difficult”. (N2)*

One national interviewee considered that within research, innovations for people with multiple long-term conditions have largely failed according to outcomes (e.g. quality of life, function), despite progress in patient experiences of care/satisfaction and in continuity of care (N1). The interviewee reflected that whilst these were good and worthy results, funding is given to innovations that show improvements in outcomes, meaning that most are pilots only and do not make it into service provision. An example of this highlighted by another interviewee is the 3D intervention[1], a 6-month comprehensive multidisciplinary review, which improved experience of patient-centred care but did not show benefits in quality of life or illness/treatment burden (N9). Similarly, another national interviewee commented that there is a gap around *“the translation of innovation into practice” (N2)*, meaning that time is spent designing an innovation, but not in encouraging implementation and uptake.

National interviewees described innovation for people with multiple long-term conditions as *“patchy” (N7), “variable and bitty” (N5),* and *“evolving” (N6),* with good practice in pockets, but that this is not consistent or widespread *(N9).* This was also reflected in sub-national interviews, with participants mentioning a variety of innovations. Often the innovations were not specific to people with multiple long-term conditions but happened to be used predominantly by people with multiple long-term conditions. Innovations mentioned were rarely connected by participants to specific care needs of people with multiple long-term conditions, unless prompted by the interviewer. Innovations mentioned that could be linked to people with multiple long-term conditions are listed in Table S4.2, alongside the care need(s) they address.

None of the innovations mentioned was for the carers of people with multiple long-term conditions.

Table S4.2. Existing innovations for people with multiple long-term conditions and their carers

Innovation	Care need(s) addressed
Offering one clinic, one appointment to address multiple concerns (e.g. vaccination clinics and doing screening/health checks at the same time)	Holistic care, person-centred care, access
Community-based / out-reach clinics, ‘drop-in’ and ‘pop-up’ clinics (e.g. in churches/mosques, community group cafes)	Access
Longer appointment times (e.g. with nurses)	Holistic care, integrated care
3D model[1]: one long annual review of a patient with multiple conditions rather than multiple separate reviews for each condition in turn	Integrated care, care coordination, continuity of care
Virtual wards (often single condition focused, but also for frailty) and remote monitoring technology (which may include external devices such as blood pressure monitors, pulse oximeters, blood glucose machines)	Access to care, self-management / care,
Self-monitoring apps or websites (often condition specific and used by proactive patients). No automatic feedback loop to clinician	Self-management / care
Complex care (CC) models / Neighbourhood initiatives / Continuity teams With Primary Care Network funding, introduced roles such as CC GP, occupational therapist, pharmacy team, health coaches. Working between health, voluntary and community sectors	Holistic care, integrated care, person-centred care, care coordination, polypharmacy
Asking patients if they want to wait for the clinician dealing with their case (non-urgent) or see any available clinician (urgent)	Continuity of care
Multidisciplinary team meetings and ‘huddles’ to discuss patients with complex multiple long-term conditions	Holistic care, integrated care, person-centred care, care coordination, polypharmacy
Continuity team for people with long-term conditions – practice nurses alongside physician associates, pharmacists, community psychiatric nurse (employed directly by the practice), care coordinators, social prescribers, health and wellbeing coaches, GPs	Continuity of care, person-centred care
Single record web interfaces that all healthcare professionals can use and share (USA)	Person-centred care, care coordination
Frailty consultant or medicines management programme to help medicine optimisation for people with multiple long-term conditions	Polypharmacy

Behaviour change programme aimed at increasing physical activity in people with multiple long-term conditions	Holistic care

While some interviewees felt that implementation decisions were often too outcomes-focused, a couple of national interviewees felt that too many innovations for people with multiple long-term conditions are not evidence-based, not implemented by research-trained clinicians (e.g. virtual wards) (N8), nor have they been *“properly validated” (N5)*. One national interviewee mentioned comprehensive geriatric assessments (CGA) as an intervention with a good evidence base, but not translated to the community setting: *“And there's pretty good evidence that CGA (comprehensive geriatric assessment) – this is an intervention not only an assessment done in older people admitted to hospital, reduces mortality, improves quality of life, and means that you spend more time in your own home in your remaining time remaining life. There's much less good evidence that trying to take the same approach in the community works.” (N5)*

Interestingly, participants considered simple things like longer appointment times, asking patients if they wanted to see the same clinician each time, and specific clinics as ‘innovative’. One interviewee commented that basic administrative support around care, e.g. ensuring that records are up-to-date, avoiding duplication of services, and improving data sharing, are needed. While the participant acknowledged that this was not innovative, it would help to address the specific needs of people with multiple long-term conditions by helping people feel safe and supported by services (N9).

Barriers to innovations for the care needs of people with multiple long-term conditions

Interviewees were asked about what they believed to be barriers to innovations for the care needs of people with multiple long-term conditions. These can be grouped into system level barriers and local level barriers, and these are described in turn below.

SYSTEM LEVEL

Focus on emergency and urgent care within NHS at the expense of multiple long-term conditions

Some interviewees noted that increasing work pressures in the NHS tend to drive a focus on emergency/urgent or same-day care, which negatively impacts non-urgent care including multiple long-term conditions reviews (S3, S4, S9). The perception that acute hospitals are not coping with demand means that services may be pushed out into the community without much resource (N1). During periods of crisis, such as a pandemic or critical incident, innovation is unlikely to be a priority (N5, N7); and investment in prevention or early-intervention/stabilisation of conditions is not prioritised (S3, S5).

Siloed, single disease focused system

Health care is often siloed and focused on single condition treatment (S1, S5, S8, S9, N3, N7, N8). Services are often organised around a single disease, via pathways (especially in secondary care) and these pathways do not acknowledge one another and come to different conclusions about care (S9):

> *“We don't routinely, at the moment, look at multiple long-term conditions as a category on its own. When you come to an innovation pathway that would then go*

> *into its individual condition specific pathway that you would look at rather than thinking about it being much more integrated across the whole."(N2)*

This single disease focus is highlighted in clinician training and specialisation, and is also an approach that patients have come to expect. A patient may present to a clinician for an issue with their foot, heart or kidney, and so will not talk about mental health or social care needs (S8). Even within the patient charity space, the charities are often single condition specific, although there are a few umbrella groups that attempt to find commonalities across charities (N3).

In addition to the focus on single diseases, healthcare services are often siloed. Communication between the siloed teams is often poor and it is left to the patients' GP to fill the gaps (N7, S9). One interviewee felt that while there is a lot of good practice happening, siloed working with no opportunities to share knowledge leads to wasted opportunities (S6). It was also mentioned that clinicians need to have knowledge of referral pathways and services and confidence to talk about care outside their area of specialism (S8). Siloed teams have different ways of working and are subject to different regulations, making integration challenging (S1). In addition, IT infrastructure is not connected across systems or teams, making sharing patient data and integrating care challenging (S1).

Patients with multiple long-term conditions are not valued in funding arrangements

Currently, a coordinated approach to caring for people with multiple long-term conditions is not valued in the system and this is reflected in healthcare funding mechanisms. Care services specifically for patients with multiple long-term conditions are not recognised in the way services are incentivised. For instance, in General Practice there is a multifocal approach to care but payment is made on a unifocal basis (S7, S9). In addition, General Practices are not rewarded for continuity of care, but for the number of patients registered and for various single-condition-specific activities (S9). Three interviewees commented that measures and innovations that would benefit people with multiple long-term conditions need to be included in service frameworks and contracts for them to be acted upon (N5, N9, S8):

> *"it's [multiple long-term conditions] not a focus. … if it was something that we were specifically measured against and harassed against, we'd measure it and we'd do something about it." (S8)*

However, one national interviewee mentioned that it would be difficult to commission for multiple long-term conditions and design multiple long-term condition pathways because of the variation in conditions and severity in conditions; and that it is easier from a national commissioning perspective to organise services around a care pathway or condition than it is to do so from an individual patient perspective (N2).

Two sub-national interviewees felt there was a lack of funding to develop and deliver innovations for people with multiple long-term conditions (S4, S6) and this was echoed, particularly in relation to ongoing funding past a pilot stage, by national interviewees (N1, N5). However, another national interviewee commented that funding is available but that it is about using funding *"to maximum effect" (N4)*, indicating that limited funds may not be directed towards multiple long-term conditions if that is not deemed to be a priority.

Lack of data and frameworks for multiple long-term conditions

Three sub-national interviewees commented on a lack of data and information on people with multiple long-term conditions to understand that population and what they need, in order to plan the appropriate workforce and services (S4, S5, S6).

LOCAL LEVEL

Workforce challenges

Challenges with the workforce were commonly mentioned as a barrier at a local level. Interviewees commented that the workforce has been through an exceptionally challenging time over the past three years during and after the COVID-19 pandemic, meaning NHS staff are *"dilapidated and tired" (N4)* and have *"nothing left to give" (N2)* to service innovation. One interviewee commented that a period of recovery may be required in the workforce before *"pushing innovation hard again" (N5)*. One sub-national interviewee commented that both clinical and administrative staff are leaving the NHS to work elsewhere in search of better pay and working conditions (S2a).

As a result of workforce capacity issues, clinicians are required to prioritise care service delivery rather than service innovation development despite their willingness and desire to be involved in innovations (S1, S4, S5, N2, N5). One example provided related to staff being able to attend huddles or multi-disciplinary team meetings, but the same staff would then not have capacity to also attend innovation steering committee sessions (S6). Another example highlighted the idea of finite resources: using staff to coordinate care reduces staff capacity for care delivery (N1). Workforce challenges can also impact ability and willingness to take part in pilot studies; relatedly, without proper uptake, it can be challenging to understand the effectiveness of innovations and any adverse effects of pilot programmes before scaling them up (N2).

Lack of 'head space', time and innovation funding

Two interviewees commented on there being a lack of dedicated time and 'head space' given to consider innovations and how best to utilise and coordinate resources (S6, N2). Many innovation teams require funding to be able to take time away from clinical duties to be involved in innovation design and planning (N2). One example was given of the possibility of using Primary Care Network development funding to have facilitated sessions involving a broad team to discuss improvement ideas (S6).

Patient specific needs and engagement in innovations

One of the greatest barriers to innovation for people with multiple long-term conditions is that not everyone with multiple long-term conditions can follow the same pathway because they have very different needs. A single service innovation would not be appropriate; the population needs to be considered at a more granular level (N1). It is also very challenging when neighbouring localities have completely different population make-ups, and hence there is structural inequality with some people having access to well-coordinated and holistic services, and others only getting the usual pathway-siloed care (S9).

Patients need clear communication about innovations and some may need help using them (N6). Lack of patient concordance can also be a challenge: *"we can have our ideas, but if a patient doesn't choose to follow that plan, that's really hard to prevent"* (S2b). Societal issues (e.g. the cost of living crisis, affording time off work, poor living conditions) may affect patients' willingness to engage with innovations (S3).

Estates

Three interviewees commented that there were not enough appropriate facilities (even just rooms) available in which to deliver innovations (S2a, N2) or for staff, including multidisciplinary teams, to share a working space (S6). That perpetuates siloed working.

Lack of risk appetite for wearables, remote monitoring, AI and adapting to new care models

According to one interviewee, there is a lack of appetite among NHS funders/commissioners regarding wearables, remote monitoring, AI and adapting to new care models (S9). They felt more could be made of the use of wearables, especially around secondary prevention of chronic disease (blood pressure, heart rate, blood oxygen saturation, blood sugar monitoring etc.), but that innovation funding for this type of care is just not available (S9). In addition, a national interviewee felt that in the technology innovation space, it can be difficult to identify innovators willing to work with the system to design and create in response to system needs, rather than first developing a product and only then trying to find the need that product might address (N2).

Key players in driving innovation for the care needs of people with multiple long-term conditions

Interviewees were asked about who they believe are the key players to drive service innovation and what might enable them to work better. National interviewees were also asked specifically about the role that the ICBs and ICSs might have in driving innovation for people with multiple long-term conditions.

Who are the key players in driving innovation for care of people with multiple long-term conditions?

Interviewees mentioned key players at different levels:

- **Macro level** (e.g, health sector, social care sector, voluntary sector, patient charities, Innovate UK)
- **Meso level** (e.g. ICSs, ICBs, Primary Care Networks, Academic Health Science Networks, Accelerated Access Collaboratives, primary care especially general practice, secondary care, local authorities, local community groups)
- **Micro level** (e.g. people with multiple long-term conditions including patient champions, carers of people with multiple long-term conditions)

Specific roles that were named included commissioners, chief executives of health care providers, medical directors, nursing directors, clinical directors, ICS personalised care leads, Primary Care Network managers, geriatric specialists, GPs, nurses, allied health professionals, practice managers in general practice, care home leads, behavioural scientists, specialist service designers, data analysts, and individual innovators. The large number of 'key' players mentioned, however, indicates that it is not clear who is ultimately responsible for the innovation of care for this group. Some interviewees mentioned that leadership at all levels needs to be connected and working towards the same vision.

What role do you envisage ICBs/ICSs having in driving innovations/service improvement for people with multiple long-term conditions?

National interviewees were asked specifically about their thoughts on the role of the ICBs/ICSs in driving the innovations and/or service improvement for people with multiple long-term conditions. Answers were predominantly around setting the strategic vision for integrated working and linking services together with joint funding that was collaborative rather than competitive (N1, N3, N7, N9, S3), and also sharing learning across the locality (N3, N4, N5, N6, S2a). Part of the vision thought important would be to ensure that robust needs assessments are completed for people with multiple long-term conditions (N2, N4), that services are then commissioned to meet these needs (N2, N4), and that the focus is on innovations and long-term benefits rather than short-term issues (N5). One national interviewee mentioned that some ICBs have innovation boards, but this is not mandated and so not all have them, and many that exist are only temporary (N3).

In addition, the provision of funding and support to foster innovation for people with multiple long-term conditions was thought to be part of the ICB/ICS role (N2, N7, S3). One sub-national interviewee mentioned that all Primary Care Networks in their region receive anticipatory funding from their ICB to deliver a complex care service which is flexible to local need (S6). Two other sub-national interviewees also commented that their ICB/ICS's 'personalisation' programme would be relevant in the care of people with multiple long-term conditions (S7, S9).

What enables the key players to work better?

All interviewees were asked about what might enable the key players to work better. The responses were predominantly related to funding, collaboration and leadership. Greater and sustained funding for innovation across all systems was the most commonly mentioned enabler. Respondents felt that pooled funding that can be used flexibly at a local level to meet local needs was important (N1, N5, N7, N9). Limited funding beyond pilot trials currently means that promising innovations largely fail to spread more widely into services (N1, N7, N9). In addition, tight funding constraints result in decisions that give little priority given to innovations that have less of an evidence base (N5).

Collaboration was felt to be key to enabling innovation. The sharing of learning is advocated across sites (S3), between roles (e.g. allied health professionals, palliative care staff, social care staff, geriatricians) (N8), across sectors (particularly voluntary sector and community services) (N6, N7, N9), and across diseases (N4). This may help reduce duplication of effort and focus innovation to better meet patient needs (N4, N5). Whilst collaboration is key, one national interviewee mentioned that clarity in the roles that the different systems and organisations play (N2) is also important.

Having strong and supportive leadership is important for innovation. Joint leadership, with joint funding, that was supportive to innovation development (e.g. empowered people to try things and to know that it would be okay if they proved not to work) are important enablers (S2a, S2b, S6, N1, N3). It is also crucial that diverse voices are involved in decision making, including people with multiple long-term conditions and the communities that support them (N3, N4, N8). This also includes providing protected time and funding to service providers to be involved in innovation from design through to roll-out (N5, N9, S6).

Gathering data and using metrics for the outcomes and experiences of people with multiple long-term conditions and their carers

Some interviewees were unaware of any data being collected specifically about or for people with multiple long-term conditions, particularly not systematically or routinely (N1, N3, N6, N7, S4, S7, S8, S9). Some were unsure what data could be collected to show if an integrated approach was benefitting people with multiple long-term conditions specifically (S7, S8, N3):

> *"I am very sceptical about how we measure integration and how we monitor integration [...] In response to a single condition, you can probably track the impact of that through RCT's [randomised controlled trials] or other uh, you know, experimental designs to see how effective that innovation is. The same goes for service pathway. If you are looking at a pathway innovation as opposed to a tech innovation, as soon as you start to drop in multiple factors into an individual, it becomes incredibly difficult to find out what has been the single thing that has changed the outcomes for that individual or that system. And that's part of the reason it's so hard to measure it at an integrated level." (N2)*

Others mentioned data that is collected that was not specific to people with multiple long-term conditions, but that would include much of this population (N6, S9). These data include: access related outcomes (e.g. attendances to services, number of contacts, duplications of contacts, referrals) (N5, N6, S1, S2a, S2b, S4, S6); health outcomes data (N5, S1, S2a, S3); patient experience feedback (S2b); patient activation measures (S1), GP Quality and Outcomes Framework data (N6, S7); and NHS England data that is linked to patient identifiers (N2). Three interviewees commented that there are a lot of data available already, but this needs to be better linked to be able to track at a patient level but also allow analyses at a population level (N3, N7, S4). One interviewee suggested that once there is a combined health record, then this may improve (S7). One of the primary challenges with existing data is there is no system identifier for a patient living with multiple long-term conditions, which would make that group more tangible (N3). In addition, data tends to be better within secondary care, but many people with multiple long-term conditions access secondary care less often than people with acute conditions, so improvements in data in primary care would be important for the population living with multiple long-term conditions (S4).

Interviewees had some thoughts on the types of data that would be important to consider collecting in the future, mostly relating to patient experiences of care, patient reported outcomes, and some clinical outcome measures. The most commonly mentioned type of data related to patient experiences of care (N1, N3, N4, N6, N7, N9, S1, S2a, S2b, S3, S8), including measures relating to:

- **continuity of care** (especially in complex conditions, not as important for people with fewer well-controlled conditions)
- **experiences of care coordination and communication** (e.g. *"Do you think your clinician knew what was happening in other areas of your care?" (N7),* whether GP and consultant can both access the same care records, having a care and support plan, whether the patients' preferences have been taken into account)
- **impact of care received on carers** (especially unpaid carers) – a sub-national interviewee commented that a challenge of trying to collect information on carers is that the health care system is not always aware of them (S4)

It is important that these measures are about the whole care experience (S8). Large patient surveys were described as *"quite broad and a bit fluffy" (N3)*, in that they do not capture what is truly important to the patient. One national interviewee commented that obtaining patient experience data is time consuming and resource intensive, and whilst there is a drive for more and better measurement, there is a balance to consider for the funding of measurement vs. the funding of service delivery (N2).

Patient reported outcomes were thought to be potentially important, such as quality of life, wellbeing measures, understanding of their conditions, and outcomes that matter to the individual patient (e.g. living and dying where you want, meeting goals that were set) (N1, N4, S1, S3).

Clinical outcome measures were also seen as useful to collect as they can act as proxy measures to assess overall care (N1, N4, N6, S1, S3). Other information worth considering included data around health inequalities (N4, S3) and staff measures (e.g. staff satisfaction) (S1, S2a, S6). Two national interviewees commented that there is a lot of quantitative data available already, but that more qualitative data may be beneficial (N4, N5, N9). A sub-national interviewee commented that there needs to be a move towards medium and long-term measures and reporting (S4).

How might a future system for service innovation that prioritises the needs of people with multiple long-term conditions and their carers be different from how service innovation happens now?

A future system for service innovation that prioritised the needs of people with multiple long-term conditions would consider that prioritisation to be desirable – currently it does not. This would increase the likelihood of clear aims and frameworks being created for decision making specific to people with multiple long-term conditions (N1, N4, N8), changes in funding models (e.g. ring-fenced money, financial incentives that are less transactional) (S7, S8, N3, N8) and potentially also lead to changes in the training of clinicians (S8).

Moving away from a single condition focus and siloed working within primary, secondary and social care services, towards holistic, person-centred care delivered by one system (N1, N2, N9 S1, S3, S9) would make it easier for patients to navigate the systems (S6). Patients need to be treated as whole people, rather than bearers of individual diseases (S8, N4, N6, N8, N9). Part of the holistic care also includes greater investment and prioritisation in primary and secondary prevention.

Longer term goals suggested by participants included having shared IT systems across services and a shared care record (S3), which would make the integration of care operationally simpler. More short-term examples provided include having a neighbourhood approach to care (S1, S3), bringing specialist clinicians into primary care for a proportion of their time (S5, S9), primary care having better direct access to secondary care services (e.g. for imaging, pathology) (S9) and having continuity teams (S9). Improved risk identification of people with multiple long-term conditions, or who are likely to have multiple long-term conditions, would help resource mapping and service configuration (S2b, S5, N2, N4, N5, N9).

More work is required in service design and research (including impact, outcome, economic evaluations of innovations) that involves diverse range of people (patient, carers, providers, ICSs, trusts) (S4, N3, N8). Services should be designed around the needs of the people rather than needs of the service, which is how many things are currently commissioned (S8, N9). The needs of carers also require greater attention as they are an invaluable resource (N9): *“there are an awful lot of unpaid carers that are doing really important work in terms of helping people to manage. But their own needs are often de-prioritised in the process” (N9).*

Lastly, some interviewees thought a future system that prioritises the needs of people with multiple long-term conditions would be data driven with decision making underpinned by data analytics, especially in relation to understanding population needs and improved risk identification (S2b, S5, N4, N7). In addition, some interviewees felt there could be a better utilisation of wearables and remote monitoring in the interest of patient self-management both to empower patients and ease burden on the service, and also to capture data that are useful for monitoring multiple conditions (S3, S9, N6):

> *"I would like to think that we'll be able to use technology so that patients will be on it – able to monitor their own disease progression and maintenance much better. And actually hand back some of the responsibility for management to the patient. I think one of the challenges over the last few years is that we've tried to professionalise care which is meant that we've actually disempowered people from looking after themselves." (S3)*

However, one sub-national interviewee mentioned that too great an emphasis on self-monitoring could lead to a focus on what can be measured, rather than what is actually important to patients (S8), and therefore should perhaps be used with caution.

In summary, it appears that the needs of people with multiple long-term conditions is not a strong driving force for care integration or innovation. There is generally a push for more holistic and patient-centred care – for all patients – but this may benefit people with multiple long-term conditions due to care needs around care coordination and holistic care. The needs of people with multiple long-term conditions need to be accorded greater priority, which might drive changes in funding, training and system structure. Serving the specific needs of people with multiple long-term conditions is currently not a priority in practice. The health care system is set up for single condition and specialism focus, which translates into siloed care and a siloed workforce. The vision is for holistic, person-centred care provided by one system, involving a range of professionals and services working collaboratively, and that stimulates and utilises advances in technology (e.g. self-monitoring, automating prioritisation processes, single care record).

References

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