Proposed governance structure for implementing house of care approach across Lothian, and further detail of three workstreams

House of care Programme Board (Figure 1)
A house of care multi-sectoral Programme Board should be established (November 2014) with a remit to ensure that strategic developments planned by NHS Lothian are focused on Hannah and consistent with the principles of the house of care. The Board and Health and Social Care Partnerships should work together to ensure effective leadership. Crucially, the Programme Board should ensure that ‘the house’ is considered as a whole and not in its component parts: it will only work if all elements are equally strong.

- Membership of the Programme Board should include senior representation from primary, community and secondary health care, social care, housing, and third sector. The Programme Board should ensure that it involves people living with long term conditions and carers in ongoing developments when relevant and appropriate.
- The Programme Board should provide strategic leadership to the early adopter sites and the three house of care workstreams outlined below.
- The Programme Board should ensure that resources are allocated responsively.
- The Programme Board should work with Health and Social Care Partnerships in their development of Strategic Plans and Integrated Care Fund Action Plans to support adoption of the house of care approach and Scottish Government Multimorbidity Action Plan across Lothian.
- The Programme Board should report to NHS Lothian’s Strategic Planning Committee.

Early adopter sites (Figure 1)
The Scottish Government has agreed to fund early adopter sites in Lothian. An Operational Group and a Learning Resource Group should be established (October 2014) to support these sites and regularly share learning.

House of care workstreams (Figure 1 and Table 1)
Three multi-sectoral workstreams representing key components of the house should be established with appropriate representation from people living with long term conditions and carers (November 2014). Each workstream should:

- Map existing Lothian building blocks for their component of the house across all sectors (February 2015).
- Identify initial learning and potential support from early adopter sites and elsewhere (April 2015).
- Work closely with the other workstreams and with Health and Social Care Partnerships.
- Agree an action plan for short, medium and long term (June 2015).
- Agree a monitoring and evaluation plan and timescales for reporting (July 2015).
Figure 1: Proposed house of care governance structure - the Programme Board would report to NHS Lothian’s Strategic Planning Committee.
### Table 1: House of care workstreams and examples of potential building blocks

<table>
<thead>
<tr>
<th>Workstream</th>
<th>A few examples of the many areas of work providing potential building blocks</th>
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</table>
| **Workstream 1:** Engaged, informed supported people living with long term conditions and carers | - Self-directed support  
- Living it Up and telehealth monitoring  
- Supported self management courses  
- Decision aids and tiered approach to psychological support  
- Peer support initiatives |
| **Workstream 2:** Health and care professionals committed to partnership working with people living with long term conditions and carers | - Holistic primary care model  
- Effective Communication for Health  
- Our Values into Action  
- Thistle Foundation resources  
- Teach back  
- Tiered approach to supported self management training including Learnpro module |
| **Workstream 3:** Organisational and support processes in place to coordinate and integrate care and support between health care, social care and third sector | - Improving links in primary care project including use of ALISS  
- Edinburgh COPD Integrated Service Model  
- Use of risk stratification to identify those who would benefit from anticipatory care planning  
- Multimorbidity approach in primary care  
- QOF ‘clinics’  
- Total Place initiative |
About Hannah

Why Hannah?

For a long time, we have planned care separately in different parts of our system (primary and community care, acute care, mental health). We have also planned around buildings, around individual services or even individual clinicians. We propose a shift toward an overarching approach which focuses on the needs of people who use all the different health and social care services across Lothian.

Recent research highlights the changing healthcare needs of the population. Life expectancy is increasing and as people live longer, they are living with multiple long-term conditions. By the age of 65, 50% of the population is living with at least two long-term conditions. Recent policy, exemplified by the Public Bodies (Joint Working) (Scotland) Act 2014, has focused on the establishment and delivery of more integrated health and social care systems.

Investigations into failing hospitals highlight the danger of a focus on systems and performance management rather than patient care. Healthcare should be designed around what people need. There must be a focus on high quality person-centred care which is safe and effective.

Systems that use a fictional patient to represent the healthcare needs of the whole population show some success in delivering integrated health and social care. Examples which use an individual patient approach as the focus of redesign include the Esther Network (used to redesign care in Jonkoping in Sweden), and ‘Mrs Smith’ (who features centrally in the integration of health and social care in Torbay). In the evaluation of the Torbay work it was found that:

The power of Mrs Smith’s story was obvious, in the connection that everyone had with her. Many service users, carers and staff knew a Mrs Smith, and they all recognised the problems she faced. Soon there was no presentation on the care trust which did not contain Mrs Smith, and she has become the symbol of the new organisation.

This development of a ‘shared narrative’ has been identified by The King’s Fund as one of the high impact interventions needed to make integrated care happen at scale and pace. We have constructed a narrative about a middle aged person with a number of long-term health conditions. Her name is Hannah.

Who is Hannah?

Hannah represents people in the 16-74 year age group with one or more long term conditions. She is 59 years old and the centre of her family. She holds down a part-time job while caring for her mother. She also loves looking after her granddaughter. Her husband has recently retired and her son is living at home while looking for a job. Many aspects of Hannah’s life such as her
family and caring responsibilities, her job and financial situation impact on her health and wellbeing. What is important to Hannah - for example, being able to play with her granddaughter - is determined in part by her health but by these other factors too. We created a profile of Hannah (Figure 1 and Appendix 1) to illustrate that her health conditions and contact with health services, although important, only represent a small part of her life. This point is reinforced by the life trajectory depicted in Figure 2.

Figure 1: Hannah’s profile

![Hannah's profile](image)

Figure 2: Life trajectory drawn by a person living with long term conditions

![Life trajectory](image)

Although Hannah is fictional we wanted her to be representative of people living with multiple morbidities. We have consulted a variety of sources to construct Hannah’s profile: health service data and records, discussion with health and social care staff, public representatives and carers.
The Scottish Patients at Risk of Admission and Readmission (SPARRA) database predicts the risk of emergency admission in the following year for patients in Scotland. It looks at previous use of health services by analysing activity such as number of drugs prescribed by GPs, Emergency Department attendances, hospital admissions and out-patient appointments. Patients are allocated a risk score of between 1% and 100% depending on their previous use, which predicts the likelihood of an emergency hospital admission within the next year. Approximately 670,000 people (72% of our patient population) in Lothian have been allocated SPARRA scores (see Figure 3). NHS Scotland’s Information and Services Division’s analysis of SPARRA has indentified four patient groups who are frequent users of the NHS: young people aged under 16 (Sophie); young adults who frequently attend the Emergency Department (Callum); frail elderly people (Scott); and adults living with long-term conditions (Hannah).

**Figure 3: Lothian SPARRA cohort 2012/13**

NHS Lothian: SPARRA profile for 72%

- Adults living with long term conditions, aged 16-74: 49% of population
- 16-55 year old adults who frequently attend A&E: 5% of population
- Frail elderly people, aged 75+: 7% of population
- Under 16: 11% of population

Approximately 440,000 people in Lothian (49% of the population) are, like Hannah, in the long-term conditions group and they account for 50% of the adult patients who experience at least one emergency admission to hospital each year. Approximately 22,000 people living with long term conditions are admitted as an emergency to hospital in Lothian each year, many more than once, resulting in approximately 32,000 emergency admissions each year.

One of the key things we have considered in choosing a patient pathway approach is the need to focus on the whole population. Research suggests that to achieve significant shifts in how we deliver our care, we need to focus on the large number of patients who use our services relatively infrequently and not only on the small number of patients who use our services a lot. The distribution of risk of admission in the long-term conditions group is very skewed with 90% of people having a risk of less than 20% (see Figure 4).
Even if only small proportions of these people get admitted to hospital, it represents a major demand on services.

**Figure 4: SPARRA risk profile for adults aged 16-74 living with long-term conditions in Lothian**

This can be demonstrated by analysis of a new linked dataset. We have linked each individual’s SPARRA score and group into Lothian’s Integrated Resource Framework. Analysis of emergency admissions for Hannah’s group, the long-term conditions cohort, shows that the majority of bed days are accounted for by people at 50% or less risk of an emergency admission in the next year (Figure 5). By improving things for the large numbers of people at moderate or low risk of emergency admission, we hope to see an improvement across the population.

We are starting to look at patterns of health care used by people in the Hannah cohort and will be including social care data once these are available: initial analyses suggest significant differences in patterns of health care use according to level of deprivation for people with a similar risk of future admission. (See Appendix 2 for more detail on Integrated Resource Framework analysis).
Figure 5: NHS Lothian Integrated Resource Framework breakdown of Lothian Long Term Conditions patients’ emergency admissions to hospital
Appendix 2: Hannah Report

Hannah’s combination of anxiety and depression with physical long term conditions is very common, and results in an even more complex situation where her mental health affects her physical conditions and vice-versa. We have estimated the number of people living with both mental and physical health conditions, which will be used to map the need for specific combinations of support. We have done this by applying rates of physical and mental long-term conditions (derived from Scottish primary care records) to the Lothian population (Figure 6). Although the number of women aged 50-74 years with mental health problems alone is similar across all levels of deprivation, the number of women with one or more physical co-morbidity increases as deprivation increases.

Evidence shows that people from the most deprived communities develop long term conditions earlier in life. Middle aged people like Hannah living in the most deprived areas experience rates of multimorbidity equivalent to those aged 10-15 years older in the least deprived areas.1 People in our most deprived communities are also more likely to have mental health problems as one of their long term conditions.

Figure 6: Physical and mental health comorbidity and the association with socioeconomic status in Lothian

Research in Scotland suggests that services are not organised to ensure resources are targeted at people with the greatest care needs, in particular, those people living in areas of multiple deprivation.12-15 Unsurprisingly, perhaps, people from these communities are most likely to have unscheduled hospital admissions.15

After talking to many people like Hannah and professionals involved in Hannah’s care and support, and reviewing the evidence, we know that
Hannah’s current care is complicated and fragmented (Figure 7). Hannah is not always an active or equal partner in the care that she needs or receives. Few people currently see or have an appreciation of the whole picture for Hannah. Conversely, people across the health, social care and third sector are not currently trained or resourced to see the whole picture for Hannah. The service map (Figure 7, Appendix 1) captures what was described by a hospital doctor as the “vortex of stuff” going on with people like Hannah, pharmacy and primary care.

**Figure 7: Hannah’s service map: the “vortex of stuff”**

There is insufficient emphasis on prevention and on the broader factors which affect Hannah’s health such as her caring role, financial situation and employment. These broader factors are often associated with deprivation. We also know that many people like Hannah are not engaged or informed enough about their health and do not receive appropriate levels of support to manage their own health. Equally the current health system is such that professionals working with Hannah tend to adopt a reactive “fix-it” approach to the immediate issue they are presented with. They may not have the time, permission, skills or knowledge to talk to Hannah as an equal partner, find out what is important to her and agree what care and support would best meet her needs in a more holistic sense. Third sector support and care is seen as invaluable by many people like Hannah, but statutory services may not refer people because of lack of awareness, time or trust.

Many aspects of Hannah’s current model of care work well but there are several ongoing issues with her quality of care at present. The trend towards
multimorbidity is likely to exacerbate these challenges. However, promising alternative approaches to delivering care in Lothian exist.

Hannah needs more person-centred care and support: care that treats her as an equal partner, recognises and supports her role in managing her health and wellbeing, and recognises the importance of prevention and anticipatory care and support. Support should be available to allow Hannah to become better informed, engaged and enabled. Her care and support needs to be more coordinated and integrated across all sectors.

The house of care

During our conversations about Hannah over the last few months, it has become apparent that the house of care model (Figure 8) provides a very useful metaphor for this approach. The house of care has gained prominence as a result of work linked to the NHS Year of Care in England and subsequent research reports by The King’s Fund. Much of the thinking about the house of care can be traced back to the chronic care model developed in the 1990s in the USA. A recent systematic review summarised evidence on the effectiveness of the chronic care model and found several positive impacts, including a ‘beneficial effect of comprehensive care on inpatient healthcare utilization and healthcare costs, health behaviour of patients, perceived quality of care, and satisfaction of patients and caregivers’.

The house of care captures the components of what is required to enable people such as Hannah to get the care and support planning she needs. The roof, foundations and side walls of the house represent the components required to enable the good conversations that are central to Hannah’s care. Crucially, the house of care only works if all components are equally strong.

Figure 8: Traditional house of care

The key elements of the house of care are:
- Hannah having a good conversation with someone to identify what is important to her, including factors not directly related to her health. For example, it might be agreed that the most important thing is to sort out Hannah’s financial worries before her health issues can be fully addressed.
• Support for Hannah to have that good conversation with relevant professionals and support for Hannah to manage things herself in a way that she wants to.

• The good conversations are translated into an ongoing care and support planning process, taking account of Hannah’s mental health needs, maximising her assets and the resources available in health, social care and third sectors. The care and support planning process continues across all sectors.

• Health and social care professionals are committed to working with Hannah in a partnership approach, and collaborating with each other and the third sector.

• Resources are allocated in a way which is responsive to Hannah’s needs identified in the care and support planning process.

• Organisational and supporting processes are provided in a way that best meets Hannah’s needs, not those of the organisations.

During our engagement about Hannah and the house of care, it became apparent that the two-dimensional model was too simple. The three dimensional model was developed to allow for the passing of time: the front of the house represents the point at which Hannah first identifies need for support and care; Hannah’s life subsequently is represented by a line through the middle of the house; the back of the house represents her end of life and palliative care support needs.

Figure 9: Three dimensional house of care representing the passage of time

Although the house of care model applies to everyone, the care and support provided is tailored to individual need which changes over time. Someone like Hannah with anxiety and depression, financial worries, and caring responsibilities is likely to need more intensive and different combinations of care and support at different times in her life.
A tale of two Hannahs

To capture how applying the house of care approach might change care for someone like Hannah, we have developed two different narratives. They illustrate how, over time, Hannah engages with health and social care service providers at different times in her life. The first represents how things might be now. The second represents an alternative vision of care that is consistent with the house of care approach. These fictional stories bring together a large body of knowledge gained from several sources including:

- One to one meetings with key professionals and people living with long term conditions and carers
- Meetings with groups of professionals
- June 18th Hannah event involving over 100 representatives of people living with long term conditions, carers, health care, social care and third sector
- Scoping literature review

As noted earlier, most of Hannah’s time is not spent engaging with the NHS or other services; instead she manages her own conditions and her own life. However, each of the ten interactions with care providers offers opportunities to help Hannah improve her capacity for self-management and to coordinate the care and support she needs. Crucially, each interaction should be focussed on better addressing Hannah’s needs – in other words, Hannah needs a person-centred system that delivers the best quality care which meets her evolving needs. We have called these interactions ‘snapshots’.

Sequence of snapshots

1. Hannah develops more than one long term health condition (multimorbidity)
2. Hannah is reviewed by her primary care team
3. Hannah gets referred to an out-patients clinic
4. Hannah attends the Emergency Department
5. Hannah is admitted to hospital
6. Hannah is discharged from hospital
7. Hannah has difficulties with her medications
8. Hannah’s anxiety is getting worse following financial strain
9. Hannah is struggling to continue to care for her mother
10. Hannah’s health deteriorates
Appendix 2: Hannah Report

Snapshot 1: Hannah develops more than one long term health condition (multimorbidity)

<table>
<thead>
<tr>
<th>Literature summary</th>
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<tbody>
<tr>
<td>In Scotland, the overall prevalence of multimorbidity is 23% but it is more common in older people (with a majority of those aged over 65 years having more than one long term condition) and more deprived communities. Multimorbidity is rapidly increasing over time, making it a growing challenge for NHS Lothian.</td>
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There is currently a lack of research on the factors which lead to the development of multimorbidity. However, it is well established that many long-term conditions can be prevented through healthy lifestyles, such as stopping smoking, eating a healthy diet and being physically active. For many who have already developed multiple long-term conditions, behaviour change can lead to substantial improvements in health.

Enabling people to live a healthy lifestyle will require NHS Lothian to work in partnership with other organisations, including local authorities, the third sector and the private sector. It is not just a question of delivering behaviour change interventions within the NHS: being healthy needs to be the easy choice. Importantly, working to produce a health-promoting environment has been found to be a key mechanism to reducing health inequalities.

Qualitative research has investigated how people’s experiences of multimorbidity vary over time, finding that the priority given to any condition varied over time and this impacted on their ability to self-manage. Research has found that additional conditions are more easily managed by patients if a cognitive link is made to the management of existing conditions.

Multimorbidity changes the clinical encounter in primary care in at least three ways: it increases the amount of clinical information to be collected; conditions progress over time necessitating re-prioritisation and revisiting management plans; and communication with other services to ensure coordination and continuity of care is needed. Longer consultation times in primary care may be helpful for people with multimorbidity, particularly since they have been shown to improve many important quality of care measures (such as patient satisfaction, more preventive advice and lower prescribing).

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<th>Future</th>
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<td>• Hannah has not been to her GP for some time but has been experiencing breathing difficulties recently. When she is seen by her GP, she has some simple investigations and has her blood pressure checked routinely.</td>
<td>• Hannah’s GP arranges for her to have a longer appointment to discuss her new diagnoses with the practice nurse. The nurse is enabled to do this by the availability and funding of longer appointments for patients with multimorbidity; the nurse has also attended training about better</td>
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pulmonary disease’ and will need to start treatment with regular inhalers and referred for some more breathing tests. She is also told that it is important to stop smoking.

- Since her blood pressure is high, Hannah is started on anti-hypertensive medications. However, Hannah is not clear which medications are for which disease and why they are necessary. Although the GP did his/her best to explain things to her, she felt that the appointment was just too rushed.

- Hannah is referred for breathing tests to try to confirm the diagnosis.

| conversations as part of health care. This longer conversation allows the nurse to take time to discuss with Hannah how her conditions relate to each other, allowing her to develop an improved ability to cope with her long-term conditions. |
| The nurse explains the importance of stopping smoking to Hannah for her two new conditions in ways that Hannah can relate to and offers a range of options for her to consider, including third sector services and peer support groups which might help her with her physical activity levels as well. |
| The nurse tells her about ‘Living It Up’, an online service designed to help her get and share information for improved health and wellbeing. She registers, and in the Flourish section, finds out ways she can support herself to self manage by watching a video. She also uses the Discover section to find a local walking group. |
Snapshot 2: Hannah is reviewed by her primary care team

Literature summary

Originally developed in the US, the Chronic Care Model has been commonly suggested as a means to improve health care for people with multimorbidity. While it has evolved over time, the six components of the Chronic Care Model are: 1. Self-management support; 2. Delivery system design conducive to effective patient care; 3. Decision support using evidence-based guidelines; 4. Clinical information systems to provide feedback and enable proactive care; 5. Healthcare system that features the above components and supports service change; 6. Linkages with community resources. A recent systematic review summarised evidence on the effectiveness of the model and found several positive impacts, including a ‘beneficial effect of comprehensive care on inpatient healthcare utilization and healthcare costs, health behaviour of patients, perceived quality of care, and satisfaction of patients and caregivers’.

Several initiatives in the UK have built upon learning from the Chronic Care Model. ‘Care Planning’ has been suggested by the Royal College of General Practitioners as ‘a powerful way of creating an environment which helps clinicians to support self management by patients of their own LTC [long-term condition]’. This goes beyond initiatives that focus on self-management alone.

The ‘House of Care’ model similarly builds upon the Chronic Care Model and seeks to improve the quality of care for those with long-term conditions. Although originally developed for diabetes care, it is being extended to meet the needs of those with multimorbidity. At the centre of the house lies collaborative care planning between an informed patient and a responsive health professional. This conversation is facilitated by the way resources are allocated and the organisational processes to encourage such communication. A key aspect of the House of Care is facilitating self-management of long-term conditions. There is generally positive evidence for benefits in terms of improved knowledge of illness, self-efficacy and physical function. Non-traditional providers, particularly the third sector, have been identified as of particular importance in facilitating self-management.

A key aspect of the House of Care is ensuring that resources are allocated in a manner that is responsive to the needs of Hannah. The academic evidence suggests that existing funding mechanisms for healthcare often serve to hinder, rather than help, the delivery of effective care for patients with multimorbidity. Existing methods for resource allocation to primary care practices in the UK may be unsuitable for fostering an adequate response to multimorbidity, particularly given the relative lack of services in those areas that are most deprived (the ‘inverse care’ law). It has therefore been argued, including by the World Health Organization, that there is a need to re-allocate funds from secondary care to primary care and the third sector. Supplemental funding for general practices to allow the provision of longer appointment times for people like Hannah with multimorbidity or living in areas of deprivation provide one example of how funding pools could be re-aligned.
to better meet Hannah’s needs.³⁹

Specific and recurrent concerns have been described by GPs about the use of hypothecated funding for disease-specific targets.⁴⁰ For example, the Quality Outcomes Framework (QOF) was viewed as reinforcing a doctor-centred consultation style, which was ill-suited to responding to a patient’s multiple needs.⁴¹ Qualitative research supported the assertion that the QOF resulted in sub-optimal care for multimorbidity,⁴² with one study finding that ‘structural constraints imposed by the QOF encouraged reductionist approaches to case-finding for depression in consultations for CHD and diabetes’.⁴³

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<th>Present</th>
<th>Future</th>
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| • Hannah goes to her GP because of increased breathing difficulties at night. Reviewing her record, the GP notes that Hannah did not attend her last outpatient appointment and asks her why, offering to refer her again.  
• At her regular blood pressure review with the practice nurse, Hannah mentions some side effects of her medication. She doesn’t mention that she rarely takes it because of these side effects. Her blood pressure is raised so the nurse changes her medication.  
• The practice nurse asks her how much she is smoking and offers to refer Hannah for smoking cessation support. Hannah says she will think about it.  
• Hannah has a self-management plan for her breathing problems which she was given by her GP a few months ago, but she is not sure where it is now. Hannah also has an Anticipatory Care Plan which describes what should happen if her breathing worsens. She is not sure if this is different to her self-management plan.  
• Hannah is referred to pulmonary rehabilitation and completes a form asking her about how “activated” she feels. She is not really sure why this is relevant to | • Hannah has known her GP, the practice nurse and receptionist for many years. They know about her family and social situation. They know she really cares about her mother and would do anything to help her. They ask to meet with her to agree an Anticipatory Care Plan which takes account of all her social issues as well as her health conditions. The Anticipatory Care Plan is regularly updated and included in a Key Information Summary.  
• Hannah has attended some classes that allow her to be more confident in explaining what she wants and how she feels when talking to care professionals. She also has been shown how to use the local library’s health information section.  
• Hannah can spend longer with either the GP or practice nurse, and not have to concentrate on “fixing” her symptoms; she tells them about what’s worrying her. She admits to the nurse that she has not been taking all of her medication because of side effects. She might have admitted that she really wants to stop smoking (her granddaughter hates it) but she is so stressed about her money worries that she can’t contemplate it at the moment. |
| her breathing problems. | • Hannah’s GP requests tests and investigations relating to two of her health conditions. Her GP refers her directly to the community diagnostic hub and arranges one follow up appointment so all the results are considered together.  
• The practice nurse has recently been on a long term conditions course where she has received training in self-management, cognitive behavioural therapy and behavioural modification techniques.  
• Hannah and the practice nurse both understand the importance of patients being “activated”, engaged and informed about their own health. |
Appendix 2: Hannah Report

Snapshot 3: Hannah gets referred to an out-patients clinic

**Literature summary**

Hannah’s experience of having several long-term conditions may mean that she has to engage with multiple sets of health services, each with a different focus which is trying to achieve distinct health goals.\(^4^4\) The concept of ‘treatment burden’ has been used to highlight the work that patients need to do to when engaging with health services, and has resulted in calls for a health service that is minimally disruptive to users’ lives.\(^4^5\) A systematic review described several forms of treatment burden for people, including the time and effort required to make sense of their clinical management, interactions with others about their conditions (e.g. discussions with health professionals and family), enacting management strategies (including taking medications or participating in self-management) and reflecting on progress.\(^4^6\) Multiple referrals to out-patient clinics are common for people like Hannah and an important form of ‘treatment burden’.

A systematic review of qualitative research of GP perspectives found a general concern about disorganisation and fragmentation of care.\(^4^7\) In particular, there was a feeling that the current system led to multiple specialists focusing on single diseases resulting in the lack of a patient-centred holistic perspective. GPs were reported to perceive communication barriers with secondary care specialists and called for ‘a balance of equals’ so that GPs and specialists worked together to improve patients’ health.

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| • Hannah is waiting for an outpatient appointment following her x-ray and breathing tests about her lung condition which is now thought to be linked to her rheumatoid arthritis. She did not attend a previous appointment. She is also expecting an outpatient appointment for her breast cancer follow-up.  
• The appointment for her lung condition arrives and is scheduled for three week’s time. The appointment for her breast cancer follow up arrives and is for 10 days time in the afternoon. It’s one of the days she has said she will look after her granddaughter in the morning. She doesn’t want to let her daughter down so becomes anxious. She intends to telephone to change the appointment date but forgets because she gets a | • Hannah has attended a course run by a local voluntary organisation geared toward supporting people to self-manage their health. She discusses her outpatient appointment with one of the peer supporters she met at the group  
• Improved access to diagnostic tests in the community means that Hannah’s GP can take ownership of much of the management of Hannah’s lung conditions in the longer term. The tests are arranged through the practice and her GP discusses the results by email with the respiratory consultant and they agree a management plan which the GP discusses with Hannah.  
• On-line appointments make it easier for Hannah to re-arrange clinic appointments around her |
<table>
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<th>Call asking her to go into work for the next couple of days.</th>
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<tr>
<td>• Hannah goes to the appointment for her lung conditions. The clinic is running an hour late. She feels quite frustrated when she has to repeat lots of information which she assumed the doctor would know from her records. The doctor is very efficient but she doesn't really understand everything he's saying. He arranges for her to have some tests which she thought she had already had done in another clinic. She is late home and therefore is unable to do her mother's shopping that day as planned.</td>
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<tr>
<td>• Hannah still intends to phone the breast cancer clinic but keeps forgetting. She decides she can look after her granddaughter and still make the clinic. However, her daughter is late to pick up the child, Hannah misses the bus and therefore misses her appointment.</td>
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<td>• The results of Hannah’s tests done in out-patients only reach Hannah’s GP after a few weeks.</td>
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<th>Carer responsibilities.</th>
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<td>• Prompts on the TV screen in the waiting area remind Hannah that she should have completed the agenda setting sheet that she was sent with her appointment letter. She writes down some of the things that she wants to discuss whilst she waits.</td>
</tr>
<tr>
<td>• Hannah is offered a video consultation for her breast cancer follow-up. She can do this at her GP surgery which saves her a time-consuming trip across town.</td>
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Appendix 2: Hannah Report

Snapshot 4: Hannah attends the Emergency Department

**Literature summary**

A retrospective cohort study in England noted that while patients with more than one chronic condition in the Quality and Outcomes Framework comprised 16% of the patient list, they accounted for 32% of all consultations. Similarly, a retrospective cohort study in Canada found that physical multimorbidity was "strongly associated with unplanned admission to hospital, including admissions that were potentially preventable." The authors noted that this increased risk was further exacerbated by coexistence of mental health conditions and socio-economic deprivation. Qualitative research exploring why patients with long-term conditions use emergency services found that they were used only when perceived as necessary and decisions were shaped by their sense of ‘candidacy’ for services, based on previous experiences.

A qualitative interview study of English health professionals (including doctors, nurses and managers in general practice and emergency departments) explored their views of patients’ use of unscheduled care and their role in reducing use. The interviewees suggested that unscheduled care use was generally a necessary component of care for those with long-term conditions and described a tension between trying to reduce its use and providing optimal care. Three approaches to reducing unscheduled care use were suggested: optimising the system (such as improving communication between primary and secondary care or better triaging or sign-posting); negotiating the system (so that formal out-of-hours service use was curtailed by making use of alternative but potentially informal systems) and optimising the patient (for example, through patient education about self-management).

**Present**

- Hannah has not been feeling well. Her rheumatoid arthritis has flared up. This has made her stressed and anxious about who will keep an eye on her mother if she is unwell and about letting her daughter down because she does not think she is well enough to look after her granddaughter at the moment. Anxiety has caused her symptoms to escalate with her blood pressure rising.
- She gets worse in the evening now experiencing breathing difficulties and goes to the Emergency Department. Secondary care do not access her medical information on her Key Information Summary.

**Future**

- When Hannah is unwell and goes to the Emergency Department the clinicians access her Key Information Summary and see her medical history which includes all her medical conditions not just the one causing her attendance at the Emergency Department.
- Since the Emergency Department staff have more detailed information available in the Key Information Summary, they are better able to understand the significance of her results. She is not actually that unwell and many of her symptoms are due to anxiety. They ask her what she would like to happen.
| Information Summary but instead ask her detailed questions about her current symptoms, medical history of this condition, and medication. Hannah struggles to answer clearly because she feels unwell. No-one asks about her caring responsibilities but this is all she is worrying about. | Reassurance and simple measures mean that she can go home and does not need admission. They are aware of the supportive community services. |
| Because she is breathless, her blood pressure is very high and her arthritis seems very painful so the doctor is reluctant to send her home. Hannah is admitted to hospital. | The specialist community team work with Hannah to enable her to manage her condition. |
| The next time she feels very breathless she phones 999 and the paramedics attend her home. They have access to her Key Information Summary and have a direct line to the Community Respiratory Team who advise that she does not need transfer to the Emergency Department and they will visit Hannah to assess her in one hour. They assess and advise her and she does not need to leave home. |
### Snapshot 5: Hannah is admitted to hospital

#### Literature summary

Continuity of care has been identified as an important goal for health services. However, the meaning of ‘continuity of care’ may be ambiguous, with at least three dimensions distinguished. Informational continuity reflects the use of information about an individual to provide appropriate care. Relational continuity refers to the existence of an ongoing relationship between a healthcare professional and the patient over time. Management continuity reflects aspiration to deliver a seamless service to patients, with a coherent approach to a patient’s care provided over time and across services.

Several studies have noted poorer continuity of care for patients with multimorbidity. Management continuity appears to be particularly threatened when patients receive shared care across different services. Problems in management continuity or information continuity are important for high quality care as qualitative research suggests that they not only compromise patient communication but may also increase the risk of medical errors and therefore the likelihood of harms being experienced by patients.

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| - Hannah is admitted to hospital late at night. She needs treatment for her COPD, hypertension and rheumatoid arthritis. There are no general medicine beds available and she is admitted to a bed in orthopaedics as a boarder.  
- Her respiratory consultant treats the COPD but has less knowledge about treating Hannah’s arthritis. There is concern that one of her arthritis medicines might be making her breathing worse and the drug is stopped. No one explains why to Hannah.  
- Hospital staff go through her medication and find that she has been taking medication from her dosette box randomly. Hospital pharmacy is asked to get in touch with the relevant community pharmacy. This involves an internet search to identify the right community pharmacy.  
- Hannah is the last patient seen on the respiratory ward round as she is a boarder. Ward staff do not have the specialist knowledge  | - On admission to hospital, Hannah’s Anticipatory Care Plan is reviewed by accessing her Key Information Summary. The admitting team discuss Hannah’s management plan with her and agree it is important to get early advice from her rheumatology specialist.  
- Hannah has been self-managing her medication successfully, with the help of medication reviews, in the community and continues to do so in hospital. Hospital pharmacy communicates electronically with her community pharmacy to make sure her repeat prescriptions are up to date.  
- Hannah’s regular carer review includes a plan for what happens if she is unable to help her mother – alternative support provided by a local carer social enterprise is provided so that her mother is safe and well in Hannah’s absence. Information that Hannah is a carer is on her Key Information Summary and social |
| they need to provide Hannah with the best quality care. | care was alerted. |
## Snapshot 6: Hannah is discharged from hospital

### Literature summary
Discharge planning aims to improve the coordination of services and care following a person being sent home from hospital.\(^{56}\) It requires information gathering and close collaboration with all those involved. A Cochrane systematic review found that discharge planning yields benefits in terms of reduced lengths of stay and lower rates of hospital readmission.\(^{57}\) A key aspect of good discharge planning is ensuring there is timely and accurate communication between hospital and community services, as well as the patient.\(^{56}\) Medication changes and rationale for changes are key pieces of information.

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<tr>
<td>• Hannah’s physical health has improved considerably following her treatment and her discharge is planned.</td>
<td>• Hannah is due to be discharged from hospital. Hannah tells staff about transport difficulties and they arrange for the local community health taxi to collect her from the hospital.</td>
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<td>• The ward staff think that Hannah should be collected from the hospital by private transport – she is not really fit enough to use public transport. Her husband does not have a car and her daughter is away on holiday so nobody is available to collect her.</td>
<td>• Hannah’s discharge from hospital is managed via a discharge hub which ensures that the relevant information from her hospital stay is communicated to her GP swiftly, for example, changes in her medication, tests and investigations and reasons for doing these.</td>
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<td>• Hannah’s final discharge letter is delayed because her notes were not transferred to her Consultant’s office until three weeks after she was discharged.</td>
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<td>• Hannah is unsure why one of her medications has been stopped. She asks her GP about this when she is seen two weeks after leaving hospital. However, Hannah’s GP is unsure why her medications have changed as the immediate discharge letter does not explain this and the final discharge letter has not yet been received.</td>
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<td>• Secondary care requested a blood test for Hannah which was taken in primary care. The results come through on a Friday evening and are abnormal: they are sent to the out-of-hours service. The out-of-hours doctor tries to interpret the</td>
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</table>
results but clinical information is limited and the rationale for test and expected result unclear. They phone Hannah to tell her the result is abnormal and ask her to come in for a further test which causes anxiety for Hannah and nearly an hour of the doctor's time.
Snapshot 7: Hannah has difficulties with her medications

Literature summary

Epidemiological studies have reported an increased use of prescription medications\textsuperscript{58, 59} and risk of adverse drug events with multimorbidity.\textsuperscript{60} A distinction between appropriate and problematic polypharmacy has been made in the academic literature. Appropriate polypharmacy occurs when medicines use has been optimised while problematic polypharmacy exists when the intended benefits from medication are not being realised.\textsuperscript{61}

Multimorbidity potentially poses fundamental challenges for health professionals to determine which treatments, or more likely combinations of treatments, yield the best outcomes.\textsuperscript{62} The effectiveness of medications are typically established in atypical patients with a single disease of interest and the generalisability of the findings of trials to patients with specific combinations of multimorbidity may be unclear.\textsuperscript{63-66} Clinical guidelines are also typically developed for the treatment of specific disease conditions, rather than combinations of conditions.\textsuperscript{67-69} Incorporating patient perspectives in treatment decisions adds further complexity. For patients with multimorbidity, application of UK National Institute for Health and Clinical Excellence ‘current guideline recommendations rapidly cumulate to drive polypharmacy, without providing guidance on how best to prioritise recommendations for individuals in whom treatment burden will sometimes be overwhelming’.\textsuperscript{70} The treatment burden imposed by medications can result in considerable negative impacts on Hannah’s quality of life.

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| • Hannah was recently admitted to hospital. During the admission, one of her drugs was changed. The discharge letter did not explain the reason for the change and her GP has no simple way of finding out. They don’t know whether to continue with the new drug or return to the old one.  
• Hannah takes several types of medication for her conditions. She is not clear why she has to take them all. There are some side effects so sometimes she is tempted to skip a dose.  
• She picks up one of her prescriptions weekly. The others are monthly.  
• One Friday evening, she drops her dosette box and mixes up her medication. Her GP practice has just closed so she calls NHS24 | • A regular medication review involving the relevant health care professionals could ensure Hannah is well informed and confident about managing her medication and that side effects are minimized.  
• Information about Hannah’s current medication is shared across all sectors electronically. The information includes rationale for starting and stopping each drug. |
and gets referred to the out-of-hours service. Not all of Hannah’s medications are available from her local pharmacist so she gets replacement of essential medication to keep her going until Monday morning. However, it takes the doctor quite a while to work it all out as not all her drugs are recorded on the emergency care summary so her plans to go out with her husband are abandoned.
Appendix 2: Hannah Report

### Snapshot 8: Hannah’s anxiety is getting worse following financial strain

**Literature summary**

The relative importance of mental health for multimorbidity was identified as an important theme in the existing literature. Poorer mental health was identified as a common consequence of experiencing physical multimorbidity but it can also result in worsening of physical conditions. Depression amongst those with a long-term condition is associated with increased use of urgent and unscheduled care and therefore increases demands on the healthcare system.

Evidence suggests that having depression may make diagnosis and treatment of physical health conditions more difficult. In primary care teams, knowledge of the patient may help with management decisions with social as well as medical interventions considered. Patient-centred consultations have often been suggested as a means of improving the quality of care, particularly for multimorbidity. Analysis of administrative data in Scotland found that patient-centredness within primary care consultations with patients who had depression was associated with greater improvements in their mental health.

In a qualitative study which interviewed GPs and practice nurses in deprived areas of Scotland, professionals described both their and patients’ ‘endless struggle’ at coping with multimorbidity. They conceptualised multimorbidity in a wide sense, including the social and psychological as well as health problems associated with deprivation. Professionals described how treating people with multiple morbidities meant more work because ‘you can open up a can of worms in a consultation’. The financial difficulties experienced by Hannah reflect these additional challenges.

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| • Hannah is worried about money. She has had little work over the past couple of weeks. She is concerned that this is because her employer knows her health is not good. Hannah recently had time off work due to sickness. Her son’s benefits are under threat.  

• Hannah’s financial worries are keeping her awake at night and also making her feel depressed. She doesn’t want to talk about the money problems with her husband because he has been depressed recently. She knows there are organisations which can offer advice but is not sure where to go and who to ask. | • Hannah’s work difficulties have been a big concern for her.  

Hannah’s GP therefore refers her to Community Advice Hub where she gets further advice and support about returning to work/support for her employer.  

• Hannah’s GP suggests to Hannah the benefits of accessing further support for her anxiety and depression. They look at the information hub (e.g. ALISS) which holds the details of third sector organisations who offer mental health support available in Hannah’s area. Hannah is very uncertain about going along to one of these organisations so her |
<table>
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<tr>
<th>Hannah’s closest friend invites her to go shopping. Although Hannah has no money to spend she goes anyway to have some distraction from her worries and to have a long chat and laugh with her friend.</th>
<th>GP refers her to a link worker attached to the practice.</th>
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<tr>
<td>Hannah’s GP feels she needs support with her anxiety and depression. She/he is aware that counselling and mental health support services are available in the third sector but can only ever remember the name of one organisation. Hannah is referred to this organisation.</td>
<td>The link worker spends an hour talking to Hannah and finds out a lot more about what’s worrying her. The link worker has a personal knowledge of many of the organisations that the GP found on ALISS and offers to go with Hannah for her first visit. They also discuss other sources of support that might help Hannah.</td>
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<td>Hannah’s GP refers her to the Citizen’s Advice Bureau based in the GP practice for advice about her financial situation and also refers her to counselling at a local voluntary organisation. Hannah goes to the Citizen’s Advice Bureau but doesn’t follow up on the counselling because she’s never been to this sort of thing before and doesn’t feel comfortable going.</td>
<td>Hannah accepts an offer to meet with an ‘peer supporter” before her first counselling session to talk about what to expect.</td>
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<tr>
<td>The Citizen’s Advice Bureau has given Hannah advice on her finances and information on third sector organizations which may also be useful to her.</td>
<td>The Citizen’s Advice Bureau has given Hannah advice on her finances and information on third sector organizations which may also be useful to her.</td>
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### Snapshot 9: Hannah is struggling to continue to care for her mother

**Literature summary**

For Hannah, help with her social needs may be more important than optimising her health conditions – the health service can help Hannah address these needs. The evidence suggests there is often a disjuncture between a medical perspective, particularly for specialists which may focus on the treatment of a specific health condition, and the patient perspective that incorporates multiple overlapping health and social considerations. To counter this, qualitative research has suggested that GPs attempt to adopt a more patient-centred approach for individuals who have multimorbidity. A study in the USA supports the hypothesis that a patient-oriented perspective might be more important in multimorbidity. The authors investigated the extent to which primary care doctors and their patients with diabetes agreed about which health conditions were most important and found that while agreement was generally reasonably high, it was lower amongst those with poorer health or additional social considerations.

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<td>Hannah’s mother has been in hospital. Discharge planning has been hampered by the difficulty in sharing relevant information between the hospital and Hannah.</td>
<td>When Hannah’s mother was discharged from hospital, discharge planning between the hospital, social care and Hannah was efficient and quick (via confidential email when appropriate) and ensured that Hannah and her mother were engaged as equal partners throughout.</td>
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<td>Following Hannah’s mother having been sent home, she has been referred by her GP for a social care assessment. The GP does not receive feedback from social care so does not hear the outcome from the assessment until Hannah’s mother comes for her next appointment.</td>
<td>A social worker designs a care plan for Hannah’s mother that includes action and support should Hannah suddenly be unable to look after her. The social worker passes this information to Hannah’s GP who adds it and relevant information to Hannah’s Anticipatory Care Plan and Key Information Summary.</td>
</tr>
<tr>
<td>Over the years, Hannah’s health has slowly deteriorated and she feels that looking after her mum has become more difficult. She raises this with her GP.</td>
<td>Hannah is referred to a Carer Support organization and offered an appointment (at a time to suit her) at one of their welfare rights surgeries run jointly with the council and Citizen’s Advice Bureau.</td>
</tr>
<tr>
<td>Hannah is referred by her GP for a carer assessment. There is variable awareness and knowledge of carer assessments.</td>
<td>Hannah looks at the telecare section of ‘Living It Up’ and finds some options she thinks might</td>
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<tr>
<td>care and has been assessed recently for carer's allowance. Hannah is concerned though that if she herself falls ill there will be no-one to look after her mother and wants to know what options for social care provision are available for her. Her mother, however, does not want to have social care support because she feels there is a stigma in accepting it. She prefers Hannah’s support and is also concerned that with social care support she will see less of her daughter.</td>
<td>help her mother. She decides to discuss these with her mother’s social worker.</td>
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### Snapshot 10: Hannah’s health deteriorates

#### Literature summary

A systematic review of GPs' perceptions of treating multimorbidity identified concerns with clinical guidelines and evidence-based medicine. This related to the evidence base underpinning the guidelines, the relevance of diseasespecific outcomes for patients with multiple conditions and this could result in guidelines increasing the complexity of patient management, since the added benefits of specific treatments for multimorbid patients are often unclear. Delivering patient-centred care, underpinned by individualised management and a generalist approach, has been recognised as important for addressing multimorbidity but also acknowledged as difficult to achieve. The longitudinal nature of the patient-GP relationship facilitates the achievement of patient-centred care.

The systematic review suggested that improving communication skills, including helping professionals discuss the pros and cons of stopping some medication with patients who may no longer be benefiting from continued use of multiple medicines, would be particularly helpful. However, other research concluded that GPs found they were not supported to stop prescribing preventive medications due to organisational challenges, contradicting clinical guidelines and concerns that patients may perceive that they ‘have been given up on’. Some experts have argued that doctors should start to think about treatment needs in a more dynamic manner. In particular, scaling back some treatments but not others may be warranted, as patients move along a continuum of needs which move from prevention towards palliation.

Research on the perspectives of people with long-term conditions finds that maintaining independence and normality are particularly important for quality of life, irrespective of age or length of time since diagnosis with a health condition. A discrete choice experiment found that people with long-term conditions in the UK are often willing to trade-off health-related quality of life for increases in control over their decisions (self-efficacy), highlighting the importance of making decisions on the basis of Hannah’s priorities.

Improving end-of-life care is a health priority. Most patients with advanced progressive illnesses, especially those with non-malignant disease, are not being formally identified for a palliative approach before they die. People need to be identified in a timely way so that they can be assessed and their care planned accordingly. Those identified are more likely to benefit from coordinated care and may be more likely to die at home. There is a large care gap between disease-modifying treatment and palliative care, which only features in the last two months of life – if at all.

A gradual, holistic and anticipatory approach in caring for people with long term conditions may be more acceptable to patients and professionals than a sudden and late switch to palliative care.
Present

- Over the years, Hannah’s health deteriorates and she finds that a combination of her poorer health conditions and the side-effects of her medications make it more difficult for her to do the things she enjoys, such as spending time with her granddaughter.
- Hannah becomes more and more breathless and during a period of ‘crisis’ is admitted overnight via NHS 24, as the patients KIS/ACP was not viewed. After a lengthy admission, most of which is spent on a Gynaecology ward, she dies during the night of respiratory failure.

Future

- Hannah has a lengthy informed discussion with a health care professional about the pros and cons of her medication and decides to stop some of them. She has agreed to try out alternative pain management techniques. They will meet again to review things in a few weeks.
- Hannah’s GP realises that her respiratory disease is reaching the stage when the issue of palliative care planning would seem appropriate. Hannah is asked to attend for a prolonged appointment to have a conversation around her future needs should her condition become palliative. The discussion manages to touch on planning for the future, including her wishes around power of attorney and resuscitation decisions. Her Key Information Summary is revised accordingly.
- Hannah says that she would like to discuss her situation with others in a similar situation and her GP refers her to a community support group. She is also offered the support of a specialist community nurse. When the time comes, she is able to die at home with appropriate levels of professional support.

These snapshots are only that. They are not intended to represent the whole of Hannah’s life – merely a few examples of the episodic interactions that Hannah has with health and care services and potential opportunities for Hannah’s care and support to be provided in a more person-centred, coordinated, collaborative way. There is no magic bullet to improve Hannah’s life, but the house of care provides a framework to redesign our approach.
Making it happen

In order to achieve these major changes in the provision of support and care to Hannah, there needs to be strong strategic leadership from both health and social care sectors. The patient pathway work and house of care approach should underpin key parts of the Health and Social Care Partnerships Joint Strategic Needs Assessments and Strategic Plans, resulting in local as well as Lothian-wide leadership. This leadership should be informed by learning from the early adopter sites for the house of care approach which are being established across Lothian. Crucially, leadership should ensure that the house is considered as a whole and not in its component parts: it will only work if all elements are equally strong.

House of care Programme Board (see Figure 10)
A house of care multi-sectoral Programme Board should be established (November 2014) with a remit to ensure that strategic developments planned by NHS Lothian are focused on Hannah and consistent with the principles of the house of care. The Board and Health and Social Care Partnerships should work together to ensure effective leadership.

- Membership of the Programme Board should include senior representation from primary, community and secondary health care, social care, housing, and third sector. The Programme Board should ensure that it involves people living with long term conditions and carers in ongoing developments when relevant and appropriate.
- The Programme Board should provide strategic leadership to the early adopter sites and the three house of care workstreams outlined below.
- The Programme Board should ensure that resources are allocated responsively.
- The Programme Board should work with Health and Social Care Partnerships in their development of Strategic Plans and Integrated Care Fund Action Plans to support adoption of the house of care approach and Scottish Government Multimorbidity Action Plan across Lothian.
- The Programme Board should report to NHS Lothian’s Strategic Planning Committee.

Early adopter sites (see Figure 10)
The Scottish Government has agreed to fund early adopter sites in Lothian. An Operational Group and a Learning Resource Group should be established (October 2014) to support these sites and regularly share learning.

House of care workstreams (see Figure 10 and Table 1)
Three multi-sectoral workstreams representing key components of the house should be established with appropriate representation from people living with long term conditions and carers (November 2014). Each workstream should:

- Map existing Lothian building blocks for their component of the house across all sectors (February 2015).
- Identify initial learning and potential support from early adopter sites and elsewhere (April 2015)
- Work closely with the other workstreams and with Health and Social Care Partnerships
- Agree an action plan for short, medium and long term (June 2015)
- Agree a monitoring and evaluation plan and timescales for reporting (July 2015)

Figure 10: Proposed house of care governance structure
## Table 1: House of care workstreams and examples of potential building blocks

<table>
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<tr>
<th>Workstream</th>
<th>A few examples of the many areas of work providing potential building blocks</th>
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| **Workstream 1:** Engaged, informed supported people living with long term conditions and carers | • Self-directed support  
• Living it Up and telehealth monitoring  
• Supported self management courses  
• Decision aids and tiered approach to psychological support  
• Peer support initiatives |
| **Workstream 2:** Health and care professionals committed to partnership working with people living with long term conditions and carers | • Holistic primary care model  
• Effective Communication for Health  
• Our Values into Action  
• Thistle Foundation resources  
• Teach back  
• Tiered approach to supported self management training including Learnpro module |
| **Workstream 3:** Organisational and support processes in place to coordinate and integrate care and support between health care, social care and third sector | • Improving links in primary care project including use of ALISS  
• Edinburgh COPD Integrated Service Model  
• Use of risk stratification to identify those who would benefit from anticipatory care planning  
• Multimorbidity approach in primary care  
• QOF ‘clinics’  
• Total Place initiative |

### Other patient pathways

Health and Social Care Partnerships, the Programme Board, early adopter sites and workstreams should explore the applicability of the house of care for Scott, Callum and Sophie as their pathways are developed.

### How will we know we have made a difference for Hannah?

Although many of the proposed changes for Hannah are very difficult to quantify, we must still monitor and evaluate implementation of the house of care approach. A monitoring and evaluation plan will be developed using a combination of quantitative and qualitative techniques (Figure 10).
Figure 11: Some ways in which the house of care approach for Hannah could be monitored and evaluated at Lothian and partnership level

- **Process measures for sharing information** eg number of anticipatory care plans shared using Key Information Summaries
- **Process measures for integrated care** eg number of referrals to third sector
- **Measurement tools of activation and enablement** eg Patient Activation Measure
- **Outcome focused assessment tools** eg Talking Points
- **Process measures for integrated care** eg number of referrals to third sector
- **Measurement tools of consultation quality**
- **Qualitative evaluation of Hannah and professionals’ experience** by academic partners
- **Analysis of Integrated Resource Framework to monitor patterns of health and social care use**
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Appendix 1: Hannah’s profile

WHAT IS IMPORTANT TO HANNAH?

BEING ABLE TO PLAY WITH GRANDDAUGHTER AND TAKE HER TO DISNEYLAND IN A FEW YEARS

Looks after 4 year old grand daughter on two mornings each week.

Visits mother once a day, and twice a day at weekends. Also responds to her mother’s telecare alarm, recently about twice a week.

Does her mother’s shopping and goes with her to the GP.

Meeting planned with social worker to discuss her mother’s future care.

Recent carer assessment with view to getting carer allowance.

Mother, 87
Early dementia, lives in sheltered housing, occasional falls, otherwise well

Husband, 67
Took early retirement from job as school caretaker. Not yet receiving full pension, prone to depression

Daughter, 31
Lives nearby, works part-time, has daughter aged four.

Son, 25
Lives at home, unemployed

Low income from her own paid work and her husband’s income.

Son’s benefits under review.

Live in 3 bedroom house (rented social housing), concerned about spare room subsidy.

Likes watching TV and shopping with close friend.

No car - Bus ride to affordable shops.

Goes to pub on a Friday night with her husband.

Works part-time shifts in local supermarket on zero hours contract.

Volunteers at local church coffee morning on Saturdays.

CARE AND SERVICES

- Hypertension
- Anxiety and depression
- Rheumatoid arthritis with lung complications
- Induction from anti-inflammatories
- Chronic obstructive pulmonary disease
- Breast cancer aged 59 (surgery, radiotherapy and long term tamoxifen)
- Overweight
- Raised cholesterol
- Heavy smoker since teenager

Outpatients
- Referred to respiratory outpatient for possible lung complications of rheumatoid arthritis but did not attend
- Referred for investigation of indigestion
- Referred for investigation of indigestion
- Follow up for breast cancer
- Accidental and emergency
- 4 accident and emergency attendances

STAY WELL ENOUGH TO BE ABLE TO LOOK AFTER HER MUM

Service contact in 1 year
- 22 practice appointments
- 75 telephone consultations
- 5 Lothian unscheduled care service consultations
- Anticipatory care plan and key information summary
- Self management plan for chronic obstructive pulmonary disease
- Smoking cessation advice x 3
- Prescriptions from 14 formulaic sections
- Monthly blood tests for arthritis medication

NHS Lothian, April 2014

Hannah’s profile has been developed for NHS Lothian’s Strategic Plan. Hannah represents adults aged under 75 living in Lothian with one or more long term conditions. Hannah’s profile is not based on a real person.
Appendix 2: Demographic profile, health care activity and costs of Lothian’s long term condition cohort as defined by SPARRA risk profile.

Introduction:
Scottish Patients at Risk of Readmission and Admission (SPARRA) is a risk prediction tool developed by ISD to predict a patient’s risk of admission or readmission in the following year using past health care utilisation data. SPARRA recognises four patient groups that are frequent users of the health service, one of which is the long term conditions (LTC) cohort (aged 16-74 years). Hannah is a fictional patient created by the patient pathways team to represent the long term conditions patient group for the strategic plan. Hannah has a SPARRA risk score within the 41-50% decile. Lothian’s Integrated Resource Framework (IRF) contains health and social care utilisation and cost data for patients in Lothian and has been linked to the SPARRA risk scores. This linked data is being used to analyse the health and social care activity and costs for the Lothian LTC cohort by SPARRA decile and to explore demographic differences in health and social care use and costs within Hannah’s risk decile.

IRF contains data on the following health care activity and costs:
- Elective inpatient admissions
- Day cases and day patients
- Non-elective/emergency admissions
- New and return outpatient attendances
- Accident and emergency attendances
- Prescribing data

IRF contains data on the following social care activity and costs though this is not yet available for 2012/13:
- Care at Home
- Residential
- Day care
- OT and Adoptions
- Direct Payments

The results presented below are preliminary and are based on data currently available in IRF.

**Objectives:**
1. To provide baseline health and social care utilisation and cost data for Lothian’s long term condition cohort as identified by SPARRA for financial year 2012/13.
2. To provide the health and social care utilisation and cost of a typical ‘Hannah’ (SPARRA risk score 41-50%) and explore how this changes with age, sex, deprivation and multi morbidity.
Demography of the LTC Cohort

Key points

- **Age:** highest proportion of patients in ageband 50-74 in all SPARRA deciles except lowest risk decile (1-10%) (Figure 1).
- **Gender:** higher proportion of females in all risk deciles apart from 61-70, 71-80 and 91-100 (Figure 2).
- **Deprivation:** proportion of patients in most deprived quintiles (Q1 and Q2) increases with SPARRA risk decile (Figure 3).
- **Multi-morbidity:** the proportion of patients with three or more long term conditions increases with SPARRA risk decile (Figure 4).
Appendix 2: Hannah Report

**Figure 1:** SPARRA LTC cohort risk deciles by agebands 16-24 years, 25-49 years and 50-74 years.

**Figure 2:** SPARRA LTC cohort risk deciles by gender.
Figure 3: SPARRA LTC cohort risk deciles by SIMD deprivation quintile
Figure 4: Proportion of patients with one, two, three, four or more than four long term conditions (LTCs) recorded in primary care within each SPARRA LTC cohort risk decile.
Healthcare activity

Key points

Acute non-elective inpatients/emergency admissions (Figure 6)
- SPARRA risk decile 11-20% has the greatest number of patients with at least one emergency admission, the highest total bed days and highest total cost.
- Cost per head for emergency admissions increases with SPARRA risk decile.

Accident and Emergency (A&E) attendance (Figure 7)
- SPARRA risk decile 1-10% has the greatest number of patients with at least one A&E attendance
- Mean number of A&E attendances increases with SPARRA risk decile.

New and return outpatients (OP) attendance (Figure 8)
- SPARRA risk decile 1-10% has the greatest number of patients with at least one new and return OP attendance
- Mean number of new OP attendances per patient increases with SPARRA risk decile; mean number of return OP attendances per patient increases with SPARRA risk decile up to 81-90% decile.

Prescribing data (Figure 9)
- SPARRA risk decile 1-10% has the highest number of patients with at least one prescription, the largest number of different items prescribed and the largest number of total items prescribed and hence highest total prescribing costs.
- Prescribing costs per patient increases with SPARRA risk decile.
Figure 6: Activity and cost data for patients with at least one emergency admission within each SPARRA LTC cohort risk decile.
Figure 7: Number of patients with at least one Accident and Emergency attendance (bottom) and mean number of A&E attendances per patient within each SPARRA LTC cohort risk decile.
Figure 8: Number of patients with at least one new outpatient attendance (bottom left) or return outpatient attendance (bottom right); mean number of new outpatient attendances per patient (top left) and mean number of return outpatients attendances per patient (top right) within each SPARRA LTC cohort risk decile

New and return outpatients

SPARRA deciles
- 1-10
- 11-20
- 21-30
- 31-40
- 41-50
- 51-60
- 61-70
- 71-80
- 81-90
- 91-100
Figure 9: Number of patients with at least one prescription (bottom left); number of different items prescribed (middle left); mean number of prescribed different items per person (top left); total prescribing costs (bottom right); prescribing costs per patient (top right).
Hannah’s risk SPARRA decile: 41-50%

Demography (Figure 1-3)

Key points
- Age – 77% are in the 50-74 year ageband.
- Gender – 51% are female.
- Deprivation – 56% are in the two most deprived quintiles
- Multi-morbidity – median of 2 long term conditions (LTCs) recorded per person in primary care; 10% of patients have 5 or more LTCs recorded.

Analysis of healthcare activity by deprivation

Key points

Acute non-elective inpatients/emergency admissions (Figure 10)
- Quintile 2 has the highest number of patients with an emergency admission, highest total number of bed days and therefore highest total cost.
- Least deprived quintiles (Q 4 and 5) have the highest cost per head.

Accident and Emergency (A&E) attendance
- Mean number of A&E attendances similar across all SIMD quintiles (range 2.0-2.2 per person),

New and return outpatients (OP) attendance (Figure 11)
- The two most deprived quintiles (Q1 and Q2) have the highest number of patients with new and return outpatient attendance.
- The mean number of return OP attendances per patient increases with decreasing deprivation.

Prescribing data (Figure 12)
- The two most deprived quintiles (Q1 and Q2) have the highest number of patients with at least one prescription.
- The two least deprived quintiles (Q4 and Q5) have the highest mean number of prescriptions per patient and highest cost per patient.
Figure 10: Number of patients with at least one emergency admission for LTC cohort 41-50% SPARRA decile by deprivation quintile (bottom left); total number of bed days by SIMD quintile (top left); cost per patients by SIMD quintile (bottom right); and total cost by SIMD quintile (top right).
Figure 11: Number of patients with at least one new outpatient (OP) attendance (bottom left) and return OP attendance (bottom right); mean number of new OP attendances per patient (top left) and mean number of return OP attendances per patient (bottom right) by SIMD quintile.
Figure 12: Number of patient with at least one prescription (bottom left); mean number of prescribed items per patients (top left); total cost of prescribed items (bottom right) and cost of prescriptions per patient (top right) by SIMD quintile.

Prescribing data for LTC cohort 41-50% SPARRA decile 2012/13
# Appendix 3: Membership of Hannah team

<table>
<thead>
<tr>
<th>Role</th>
<th>Name</th>
<th>Position</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Clinical Lead</strong></td>
<td>Carl Bickler</td>
<td>General Practitioner</td>
</tr>
<tr>
<td><strong>Public Health</strong></td>
<td>Rachel Hardie</td>
<td>Consultant in Public Health</td>
</tr>
<tr>
<td></td>
<td>Vittal Katikireddi</td>
<td>Specialist Registrar</td>
</tr>
<tr>
<td></td>
<td>Martin Higgins</td>
<td>Senior Health Policy Officer</td>
</tr>
<tr>
<td></td>
<td>Annette Gallimore</td>
<td>Senior Public Health Researcher</td>
</tr>
<tr>
<td></td>
<td>Leonie Hunter</td>
<td>Senior Public Health Researcher</td>
</tr>
<tr>
<td><strong>Strategic Planning</strong></td>
<td>Libby Tait</td>
<td>Associate Director – Strategic Planning</td>
</tr>
<tr>
<td><strong>Public Involvement</strong></td>
<td>Lesley Baxter</td>
<td>Public Involvement Coordinator</td>
</tr>
<tr>
<td><strong>Modernisation Team</strong></td>
<td>Lesley Morrow</td>
<td>Service Improvement Manager</td>
</tr>
<tr>
<td><strong>Social Care</strong></td>
<td>Tom Welsh</td>
<td>Integration Manager – Midlothian Partnership</td>
</tr>
<tr>
<td></td>
<td>Marna Green</td>
<td>Senior Manager, Assessment and Care Management, Edinburgh North</td>
</tr>
<tr>
<td></td>
<td>Nikki Conway</td>
<td>Senior Manager, Assessment and Care Management, Edinburgh South</td>
</tr>
<tr>
<td><strong>Data Visualisation</strong></td>
<td>Becky Kaye</td>
<td>Senior Information Analyst</td>
</tr>
<tr>
<td><strong>Third Sector</strong></td>
<td>Diana Noel-Paton</td>
<td>Chief Executive – Thistle Foundation</td>
</tr>
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