APPENDIX D:

Patient Stories – Case Studies
Mr. Foster lives with his wife in Cockermouth. He suffers from chronic obstructive pulmonary disease (COPD) and chronic heart failure. However, he is also the primary carer for his wife, who suffers from dementia.

Without sufficient information about his chronic conditions, Mr. Foster feels compelled to go to hospital if he suspects anything is wrong:

- Mr. Foster is diagnosed with chronic heart failure
- Mr. Foster goes to the GP once a month to get his vital signs tested, often waiting a long time for his appointment
- After complaining of feeling tired, Mr. Foster’s wife urges him to visit A&E, where he is admitted for further testing, and eventually finds out he has low O2 saturation levels
- Mr. Foster’s GP wonders why he did not come to him directly, and the local hospital staff do not understand why Mr. Foster has come in

Mr. Foster is worried about the impact of regular hospital trips on caring for his wife.

Mr. Foster is reliant on his children taking time off to care for his wife in his absence.

Mr. Foster finds the situation stressful, especially the delay in getting results.

Mr. Foster feels frustrated.

A telehealth service provides the health system with the information needed to treat Mr. Foster in a less disruptive manner, reducing unnecessary hospital visits:

- Mr. Foster is diagnosed with chronic heart failure
- A telehealth solution is set up to provide support to Mr. Foster, with the support of a one-to-one community nurse, and minimise the need for him to visit his GP or A&E.
- After complaining of feeling tired, Mr. Foster’s vital signs recordings identify that he has unexpected low O2 saturation levels, resulting in the prescription of non-invasive ventilation overnight.
- Mr. Foster’s GP feels that he is in a position to make more informed clinical prescriptions, to support and manage Mr. Foster’s care; the local general hospital is dealing with less unscheduled care.

Mr. Foster is worried about the impact of regular hospital trips on caring for his wife.

Day-to-day, Mr. Foster and his family can look at his health information.

Mr. Foster is relieved that he does not have to undergo additional testing.

Mr. Foster feels more supported and able to continue caring for his wife.
Mr. and Mrs. Dudley, who live at home together, are both 83 years old.

Services each respond appropriately to the situation they assess

- Mr. Dudley phones 999 late in the evening because he believes his wife is dying
- The ambulance arrives and Mrs. Dudley is too weak to speak. She is taken to hospital and the next day her GP is informed
- The GP phones the hospital to explain that Mrs. Dudley has recently expressed a wish to die at home. This discussion is recorded on the practice patient notes but the GP isn’t sure if Mr. Dudley is aware
- The next day, a hospital consultant explains to Mr. Dudley that his wife had discussed dying at home with her GP. Mr. Dudley agrees that his wife should return home. While discharge is being organised over the next few days, Mrs. Dudley dies in hospital

Mr. Dudley is scared and doesn’t know what to do
Mr. Dudley is upset. However, he feels he cannot cope by himself, and that his wife is best in hospital
Mr. Dudley wanted to meet his wife’s wishes and is sad that he was not able to do so

In future, Mr. Dudley would have a different experience of integrated care....

- Mr. Dudley phones 999 late in the evening because he believes his wife was dying
- Mr. Dudley speaks to David in the ambulance control centre. David has access to Mrs. Dudley’s care record and can see that the ICC has developed an end of life plan with Mrs. Dudley and that she wants to remain at home
- David contacts the ICC out of hours team who arranges for a member of the ICC team to visit Mrs. Dudley at home within the hour. The GP calls Mr. Dudley to explain the support that will arrive. The GP arranges for a sitting service to stay with Mrs. Dudley for the next 48 hours
- Mrs. Dudley dies two days later, in her own home. The GP calls Mr. Dudley a few days later to see if he needs any social care help for a short while with the shopping, cooking and cleaning

Mr. Dudley is scared and doesn’t know what to do
Mr. Dudley is reassured that there is a plan which will help meet his wife’s wishes
Mr. Dudley is pleased that he can meet his wife’s wishes
Mr. Dudley is sad his wife died. However, he is pleased that he was able to look after her at home
Mary is 75 and has noticed a gradual loss of vision particularly when light is poor. Her daughter persuades her to visit the local optometrist.

**Current state.**

<table>
<thead>
<tr>
<th>Event</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>Mary is feeling scared - she’s been worrying for some time about her vision</td>
<td>Optometrist carries out test and explains that Mary has developed cataract in one eye and will need surgery. Optometrist refers Mary to GP who makes referral into acute ophthalmology service.</td>
</tr>
<tr>
<td>Mary is still apprehensive and is worrying about whether her daughter will be able to take time off to take her to all the appointments</td>
<td>Mary attends outpatient clinic at Whitehaven. She is seen by a consultant who lists her for surgery and informs her that she will need to attend for pre-assessment.</td>
</tr>
<tr>
<td>Mary attends pre-assessment clinic then following week attends for surgery.</td>
<td>Mary attends pre-assessment clinic then following week attends for surgery.</td>
</tr>
<tr>
<td>1 week post op check plus 4 weeks later Mary attends hospital for follow up appointment. All is fine.</td>
<td>1 week post op check plus 4 weeks later Mary attends hospital for follow up appointment. All is fine.</td>
</tr>
</tbody>
</table>

**In future Mary would not have to attend hospital so frequently. There are fewer steps in the process and she would feel more involved in the process.**

<table>
<thead>
<tr>
<th>Event</th>
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<tbody>
<tr>
<td>Mary is feeling scared - she’s been worrying for some time about her vision but is able to discuss this with the optometrist</td>
<td>Optometrist carries out test and explains that Mary has developed cataract in one eye. The optometrist goes through a patient decision tool with Mary and she decides that she would like to be referred. Optometrist directly refers her to hospital service.</td>
</tr>
<tr>
<td>Mary is still apprehensive but she feels she has made a positive choice and is pleased that she has everything done on one visit</td>
<td>Mary attends a one stop clinic where she is seen by an ophthalmic nurse, has a pre-assessment and is seen by the consultant.</td>
</tr>
<tr>
<td>Mary vision is much better. She was able to walk to the optometrist in town. So much easier than having to get to the hospital.</td>
<td>Mary attends for surgery. Mary gets follow up phone to check on her within next week and then 4 weeks later Mary visits her local optometrist for a follow up appointment. All is fine.</td>
</tr>
</tbody>
</table>
Mr Smith lives with his wife and two young children in Penrith. He is a self-employed builder.

Mr Smith is worried about losing work and wants his surgery done as soon as possible to avoid loss of income. He wants an efficient service, one that he can rely on and that causes as little disruption to his life as possible.

Mr Smith notices a lump in his groin and knows himself that he has a hernia. He sees his GP who refers him to a GP run hernia clinic.

Mr Smith and the GP surgeon realize that his operation is not suitable to be done in a community hospital and he needs to be referred to an acute hospital specialist. Mr Smith receives an appointment to attend the Cumberland Infirmary where he sees a surgical registrar. He is put on a waiting list for surgery and booked for a pre-assessment appointment.

Mr Smith’s surgeon is busy with more urgent cases so it is sometime before he can accommodate Mr Smith operation. When he does, Mr Smith has two weeks’ notice. Unfortunately a more urgent case comes up on the day and Mr Smith’s operation is cancelled.

Mr Smith is frustrated that he has now seen three doctors, still has to return to the Cumberland Infirmary for his pre-assessment and still has no idea when his operation will be.

After 2 further cancellations on the day Mr Smith has his hernia surgery carried out.

Mr Smith is relieved but vows that if he needs surgery again he will go elsewhere for treatment.

An integrated surgical service with separation of elective and unplanned surgery provided a more reliable service.

Mr Smith notices a lump in his groin and knows himself that he has a hernia. He sees his GP who refers him to an integrated surgical clinic.

Mr Smith is seen by a GP surgeon who discusses his case with his acute hospital consultant colleague who is working in a clinic in parallel in Cockermouth Cottage Hospital. Mr Smith undergoes his pre-assessment and is given a choice of dates for surgery before he leaves.

Mr Smith attends on the planned date for surgery at the Surgical Treatment Centre at the WCH.

Mr Smith has a follow up phone call from the surgical team to confirm that he has recovered well.

Mr Smith is re-assured that he has been given access to all options of treatment and relieved that he can make plans around his date of surgery.

Mr Smith is pleased with the service.

Mr Smith is an advocate for the local surgical service.
Mr. Kelly, aged 80, has heart and breathing problems. He’s been prescribed eight different medications by his GP and hospital specialist. Mr. Kelly sometimes misses doses because taking all the meds as prescribed gives him nausea. He has had several recent admissions to hospital.

Services each respond appropriately to the situation they assess

- A social worker, a community nurse and an occupational therapist and physio visit Mr. Kelly at home to do assessments following his last hospital admission.
- A homecare worker makes daily visits to Mr. Kelly to help with household tasks, the district nurse visits to monitor his condition and medication adherence, and a physio assistant takes him through an exercise regime.
- Mr. Kelly is out when the district nurse visits. This means he misses his medication.
- Lack of medication means Mr. Kelly suffers from nausea and is readmitted to hospital.

Mr. Kelly cannot remember what all these people wanted him to do.

Mr. Kelly is confused by all the visitors who tend to him for different reasons.

It is a sunny day so Mr. Kelly feels able to go out.

Later that day, Mr. Kelly is readmitted to hospital.

In future, Mr. Kelly would have a different experience of integrated care...

- Mr. Kelly lists continuing to visit his grandchildren in a nearby town and getting to church on Sundays as two things which are very important to him. The information about his needs and goals are captured in a care plan which is shared with Mr. Kelly and his family.
- With input from other members of the integrated care team, his GP Practice is able to complete a comprehensive assessment of Mr. Kelly’s health and social care needs, including simplifying his medication regime.
- A member of the ICC team, Claire, visits Mr. Kelly for a few months to provide practical assistance with household tasks, Claire takes Mr. Kelly through an exercise programme and helps Mr. Kelly to monitor his vital signs and adjust his medication accordingly.
- Mr. Kelly's daughter visits him regularly to check his medication and Mr. Kelly works hard at his medication compliance and physiotherapy so he is well enough to maintain his visits to his grandchildren and go to church on Sundays.

Mr. Kelly is happy that his preferences are being taken into account.

Mr. Kelly is pleased not to have to take so many tablets.

Mr. Kelly feels comfortable with Claire who visits regularly.

Mr. Kelly is able to continue doing the things he enjoys, while keeping to his medical regime.
Mr Foster, an elderly resident with no living relatives, is admitted to hospital following a fall...

### Services each respond appropriately to the situation they assess

<table>
<thead>
<tr>
<th>Event</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital staff notice that Mr. Foster has difficulty remembering things and appears disorientated.</td>
<td>Mr. Foster feels lonely</td>
</tr>
<tr>
<td>Mr. Foster is discharged, however his forgetful state continues and as he lives alone, it goes unnoticed. One day he forgets to close the front door when he leaves</td>
<td>Mr. Foster is confused as to why he isn't at home</td>
</tr>
<tr>
<td>Mr. Foster's flat is burgled and damaged whilst he is out. He is placed into respite care whilst the flat is repaired.</td>
<td>Mr. Foster is upset and wants to be back home</td>
</tr>
<tr>
<td>Whilst in an unfamiliar environment Mr Foster's cognition deteriorates even further. By the time his flat is repaired, he has been placed in a care home.</td>
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</table>

### In future, Mr Foster would have a different experience of integrated care.....

<table>
<thead>
<tr>
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</tr>
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<tbody>
<tr>
<td>Hospital staff notice that Mr. Foster has difficulty remembering things and appears disorientated. They contact the Integrated Care Community, who arrange for him to be seen by a member of the memory team.</td>
<td>Mr. Foster understands he needs help and enjoys the visits to the Mind Gym</td>
</tr>
<tr>
<td>Mr. Foster is seen by the memory team while in hospital and develop a care plan for discharge. He starts medication to slow his decline and visits a group to manage his memory difficulties.</td>
<td>Mr. Foster feels he is a little more in control of his memory problems</td>
</tr>
<tr>
<td>An occupational therapist who is a member of the ICC visits him at home to place environmental memory aids around his home and speaks regularly with his memory group to track his progress.</td>
<td>Mr. Foster has begun to volunteer at the Barrow Society of Artists and feels valued</td>
</tr>
<tr>
<td>Mr. Foster is able to live independently monitored by the memory service. He manages his finances and continues to meet with the memory group which has reduced his isolation.</td>
<td></td>
</tr>
</tbody>
</table>
Mrs. Smith is aged 81 and lives on her own, with no family in the local area...

Services each respond appropriately to the situation they assess

Mrs. Smith has a fall and pulls her pendant alarm, which triggers a call to an ambulance

Mrs. Smith is upset but has used the alarm before and knows help will come

Mrs. Smith is taken to hospital for tests, despite no physical damage, and a serious skin infection is discovered

Within 2 hours, a GP visits Mrs Smith and discovers a serious skin infection. She prescribes a course of IV antibiotics and creates a care plan with Mrs. Smith

Mrs. Arthur confides in the nurse that she is worried about falling again

Mrs. Smith is admitted to hospital so that she can receive a course of IV antibiotics

A member of the ICC team brings the medication to Mrs Smith and a nurse administers IV antibiotics at home. They identify trip and falls hazards and arrange for safety equipment to be installed

Mrs. Arthur is happy to be in her own home and calls her family to visit her

Mrs Smith feels very anxious about going home and her nurse suggests that she may feel safer if she was moved to a care home

On Friday, Mrs Smith is moved to a nursing care home

In future, Mrs. Smith would have a different experience of integrated care.....

Mrs. Smith has a fall and pulls her pendant alarm. An ambulance is called. Assessing no physical damage, the ambulance crew make a referral for a GP home visit

By the following week Mrs Smith has regained her strength and her care worker takes her for walks to build up her confidence. The GP reviews the care plan and the care worker checks in regularly with Mrs. Smith

Mrs. Smith is unhappy because she doesn’t want to be in hospital

Mrs. Smith is upset but has used the alarm before and knows help will come
Currently Mr Smith is passed back and forth as his treatment progresses

- Mr Smith has persistent shoulder pain
- Mr Smith is referred directly to an Orthopaedic surgeon. He receives a steroid injection & is discharged for physio
- Symptoms persist & GP has to refer to ESP for further 2 steroid injections. When this fails to resolve symptoms, Mr Smith then has to be referred to Orthopaedic Surgeon again.
- Seen by Orthopaedic Surgeon, sent for U/S scan, wait for review in clinic, finally listed for surgery

- Mr Smith wants this sorted with minimum disruption to his work
- Mr Smith perceives the surgeon has no test results & feels basic treatment has not been undertaken
- Mr Smith is frustrated by delays & multiple visits to different people
- Again frustrated by delays & multiple separate appointments

In an integrated MSK service this will be streamlined

- Mr Smith has persistent shoulder pain
- Mr Smith is referred to CATS. Assessed by ESP, steroid injection & physio arranged.
- Mr Smith is reviewed at CATS after 6 weeks. Further steroid injection, U/S scan at same time.
- Reviewed after 6 weeks by surgeon and listed for surgery

- Mr Smith wants this sorted with minimum disruption to his work
- Mr Smith has treatment started at same time & more time to discuss issues
- Mr Smith is happy as visits minimised & given appointments in advance
- Again happy that appointments are made early so he can plan time off work
Edith is 36. She is a working mother who struggles to manage her work and home life. She has a young son, Robert who is 4 years old and has a fever.

Primary care has been difficult for some patients to access, putting pressure on other parts of the health system

- Edith comes home from work at 6pm to find her son has come back from nursery with a fever
- Edith rings her GP but they are closed so she takes him to A&E
- In A&E, Edith is tired and Robert gets progressively worse whilst waiting three hours to be seen
- Robert's treatment is transactional and fast; there are no broader checks, such as whether Edith is coping or whether Robert's injections are up-to-date

Edith is uncertain what the best course of action is and who to contact
Edith feels stressed and wants to do the best for Robert
Edith senses that the doctors feel overwhelmed
Edith is grateful for treatment and A&E as a place for care is reinforced

In future, patients will have better access to primary care and know how to get it

- Edith comes home from work at 6pm to find her son has come back from nursery with a fever and calls the ICC centralised number
- The ICC workers assess Edith over the phone and conclude that she does not need to go to A&E. Edith receives an appointment for 8.30pm in a GP practice close to their home which does 18 hour care
- The GP sees her son and accesses his health record. They assess Robert, give him the medicine he needs and do a basic check against his health record
- If it was more serious the GP could give Robert emergency treatment and send to the short stay Paediatric Assessment Unit

Edith understands that the ICC can direct her to the most appropriate care
She is relieved and reassured, feeling confidence in the system
Edith is reassured and feels confident to see the episode through
A record is taken of the event and communicated to the family's GP
Hayley is 43. She is fit and well. After playing a tennis match yesterday, she experienced significant pain in her right knee, which has become worse overnight.

**Sometimes the pathway to receive planned care is complex and disjointed...**

<table>
<thead>
<tr>
<th>Event</th>
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<tbody>
<tr>
<td>Hayley goes to her GP who advises her to have Rest Ice Compression and Elevation. He gives her some pain killers and tells her to come back if she doesn’t improve.</td>
<td>Hayley doesn’t know what is wrong with her and why rest ice compression is not working.</td>
</tr>
<tr>
<td>After a week, Hayley is still in pain and unable to work. She is using an old pair of crutches that her friend gave her. She returns to her GP who refers her for an MRI scan.</td>
<td>Hayley is off work for weeks, she can’t drive a car and is struggling to leave the house.</td>
</tr>
<tr>
<td>It takes a further two weeks to get the MRI scan done, and 48 hours for that report to get back to her GP. She has an anterior cruciate ligament tear and needs to be referred to a surgeon.</td>
<td>Hayley is frustrated and worried she cannot get another four weeks off work for the pain.</td>
</tr>
<tr>
<td>Four weeks later, Hayley sees an orthopaedic surgeon who arranges an operation in a further four week’s time.</td>
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</table>

**In future, the pathway will be simpler, understood by all clinicians and joined up...**

<table>
<thead>
<tr>
<th>Event</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Hayley goes to her GP who books her an MRI scan later that day. He gives her pain killers in the meantime and refers her to Physio who give him some crutches.</td>
<td>Hayley feels that the GP takes her seriously and is offering her the best possible care.</td>
</tr>
<tr>
<td>Four hours later she sees the GP again who informs her she has an ACL tear. She is referred to a knee clinic and is seen by a physio and consultant the next day. An operation is booked for two weeks later.</td>
<td>Hayley is satisfied that she now knows what is wrong and can see a specialist the next day.</td>
</tr>
<tr>
<td>Prior to the operation Hayley has daily physio to strengthen her ITP band and other muscles to be ready for the operation. She takes anti-inflammatory to bring the swelling down until 48 hours to the operation.</td>
<td>Hayley feels that the system is working together to help her recover faster.</td>
</tr>
<tr>
<td>On arrival home, patient, physio and GP get an email detailing her operation and rehabilitation post-operative. The physio continues to see her for 6 weeks.</td>
<td>Hayley is happy to see progress and is looking forward to playing tennis again.</td>
</tr>
</tbody>
</table>
Nora is 80. She lives alone in sheltered accommodation in the same block as her elderly brother, and has a niece who discusses care with her GP. She is isolated and lonely and is not compliant with either her medication or hospital appointments. Nora is a heavy smoker.

**Urgent care has been stressful when patients need support...**

- Nora’s niece visits and finds her aunt acutely unwell with a chest infection
- Neither Nora nor her niece know whether or not she has taken her medication, or the right one as she is on 16 different medications. Unclear on what to do, her niece takes her to A & E – the second time in a week
- Once home, Nora is referred to the respiratory outpatient department and told to visit yet another on-call medical team
- Three weeks later, Nora is admitted back to hospital. Her physical and mental state has deteriorated and she is discharged into a care home

**Nora does not like going to hospital, even when she is unwell**

**Nora is tempted not to attend the appointment, she has been to so many already**

**Nora hopes that she will be less isolated in a care home**

**In future, patients’ needs will be met at home**

- Nora’s niece visits and finds her aunt acutely unwell with a chest infection. She calls her case manager, who refers Nora to the rapid response team for assessment and her GP conducts a home visit
- The GP and ICC make a health and social care assessment and step up Nora’s package to include community pulmonary rehab and a falls assessment. She also starts using a medication tracker she receives
- Nora’s care plan is discussed with the geriatric expert in the ICC, who recommends medication changes to reduce risk of future infections. She also rationalises her outpatient appointments.
- Nora feels better and after four weeks, her care package is stepped down to weekly review by her case manager

**Nora is relieved that she can be seen at home**

**Nora feels as though her care is being taken seriously**

**Nora feels more confident about managing her health and spends more time with her brother**
David is a 35 year old with Crohn’s disease.

David is seen by multiple doctors and has a poor experience of care:

- David has recently had his bowel partially resected and a colostomy fitted. However, his stoma bag has cause persistent cellulitis and the tissue around the colostomy is chronically inflamed.
- David goes to hospital and is prescribed antibiotics. However, one week later is admitted back to general surgery as these are ineffective.
- David is passed from doctor to doctor, and has to explain his disease to each new person in the system.
- David is finally prescribed different antibiotics, but is given no assurance as to whether these will be more effective.

**David feels exhausted by the constant problems and flare-ups of Crohn’s disease**

**David feels frustrated as he feels he cannot support his family if he is constantly going to hospital**

**David feels that no one has explained the care he needs and how it impacts on his life**

**David feels anxious at the lack of clarity and as though he cannot enjoy life to the full**

In future, David would:

- David has recently had his bowel partially resected and a colostomy fitted. However, his stoma bag has cause persistent cellulitis and the tissue around the colostomy is chronically inflamed.
- David goes to hospital and is prescribed antibiotics. He is told that if the antibiotics are not working within one week, that he can speak with his GP to prescribe another type.
- David discusses his antibiotics with his GP, who runs through his medical history to find the most effective ones. He explains any side-effects and how David can best manage these.
- David receives his new antibiotics and agrees with his boss that he can work from home if he experiences another severe flare-up.

**David feels exhausted by the constant problems and flare-ups of Crohn’s disease**

**David does not like going to hospital so is relieved that he can follow up with his GP**

**David feels comfortable speaking with his GP**

**David understands how he can best manage his condition and feels less worried**
Jameel is a 57 year old smoker with three children; he is the main breadwinner of the family. He is diabetic, has high cholesterol and blood pressure and was diagnosed with ischaemic cardiomyopathy a year ago.

**Jameel goes to A&E but does not find the treatment satisfactory or helpful**

<table>
<thead>
<tr>
<th>Event</th>
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<tbody>
<tr>
<td>Jameel's wife encourages him to go to hospital after experiencing shortness of breath</td>
<td>Jameel takes a taxi to A&amp;E but faces a long waiting period, during which time he is not informed as to whether his symptoms are serious</td>
</tr>
<tr>
<td>Jameel is frustrated, as he has had to wait at A&amp;E several times</td>
<td>Jameel worries that he cannot prevent another trip to hospital, and how this impacts his family</td>
</tr>
<tr>
<td>Jameel is anxious about the possibility of not being around to look after his family</td>
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</table>

**In future, Jameel would be better informed and receive care closer to home**

<table>
<thead>
<tr>
<th>Event</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Jameel's wife encourages him to go to hospital after experiencing shortness of breath</td>
<td>The GP listens to Jameel's symptoms and medical history and agrees to conduct a home visit</td>
</tr>
<tr>
<td>Jameel feels happier that he can be seen in his own home as he cannot drive</td>
<td>Jameel feels better informed and that he can control his health and support his family</td>
</tr>
<tr>
<td>Jameel's confidence grows and he feels that he can enjoy life despite his health problems</td>
<td></td>
</tr>
</tbody>
</table>

Jameel is sent home and his wife explains how worried she gets whenever he goes to hospital.
Karen is a 45 year old mother of one, with a history of drug and alcohol abuse. Growing up in an abusive household, she has received very little help for her condition, and unable to hold down a job, she is forced to move between different housing.

**Karen’s pain is not well-managed, and she finds herself trapped in a negative cycle**

<table>
<thead>
<tr>
<th>Karen has been complaining of chronic abdominal pain, possibly due to chronic pancreatitis or function bowel disorder</th>
<th>As the pain gets worse, Karen is hospitalised. This ends up happening once a week, and whilst a number of treatments are offered, none have reduced the pain significantly</th>
<th>Karen sees a number of different doctors in hospital and there are concerns for narcotics seeking behaviours</th>
<th>Karen returns home and continues to care for her child as best she can</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Karen avoids her GP because he does not understand her</strong></td>
<td><strong>Karen feels she does not have anyone to contact on bad days</strong></td>
<td><strong>Karen feels she needs to repeat herself at every interaction, and feels discriminated against</strong></td>
<td><strong>Karen returns to taking drugs to cope with the debilitating chronic pain</strong></td>
</tr>
</tbody>
</table>

**In future, the system would address all aspects of Karen’s health**

<table>
<thead>
<tr>
<th>Karen has been complaining of chronic abdominal pain, possibly due to chronic pancreatitis or function bowel disorder</th>
<th>The GP explains the different treatment options available to Karen, but explains that she will need long-lasting coping mechanisms to stop using drugs and alcohol</th>
<th>The GP puts Karen in touch with the ICC team who visit her at home to put together a long-term care plan and discuss her difficulties around job and housing security</th>
<th>With the right pain management, Karen begins attending job interviews and is saving to be able to rent her own flat</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Karen reaches out to her GP in the knowledge she will be listened to</strong></td>
<td><strong>Karen is nervous but positive about the future</strong></td>
<td><strong>Karen begins to feel supported for the first time and thinks about her future</strong></td>
<td><strong>Karen feels more secure in her ability to provide for her daughter</strong></td>
</tr>
</tbody>
</table>
Eve is 85 years old and lives with her husband George on a very low income in social housing. Eve suffers from a painful and debilitating back condition and finds it increasingly difficult to walk or take trips outside the home. She recently tripped and fell at home, fracturing her hip.

Eve is taken into the care system and feels she cannot live independently

- Eve is admitted to hospital and her fracture is surgically treated. A minor heart attack during surgery results in her staying in hospital for 7 days
- At discharge, Eve is admitted to a care home to recover and told that when she returns home there would be daily visits from carers
- Eve returns home, and the carers arrive, but the care plan is poorly communicated leading to confusion
- Eve worries that she will fall at home again, and is worried about the possibility of another surgery and recuperation

Both Eve and George are worried about her health and whether she can stay at home

George is worried about his ability to cope with caring for Eve

Eve and George feel lost in the care system, and wish they could just visit the family GP

George is worried about Eve but does not know what to do

In future, both Eve and George’s preferences would be taken into account

- Eve is admitted to hospital and her fracture is surgically treated. A minor heart attack during surgery results in her staying in hospital for 7 days
- At discharge, Eve is admitted to a care home to recover. An ICC worker sits with Eve and George to understand their care preferences and explain the role of the carers and their GP
- The carers have a preliminary visit to the house, explain their timetable and assess the home for fall risks, adding support structures where possible
- Eve’s GP and carer communicate her progress; Eve is starting to take walks and trips outside her home again

Both Eve and George are worried about her health and whether she can stay at home

Eve and George are comforted they can still involve their family GP of 20 years

Eve and George are happy with the care package

Eve feels more confident both inside and outside her home
Mrs Smith is a 65 year old lady who lives alone in a rural area in West Cumbria. She has been diagnosed with metastatic breast cancer after a recent admission to West Cumberland Hospital. She is known to the Primary Care Team and has been referred to the Community Palliative Care Clinical Nurse Specialist and is currently waiting to see Oncology.

Mrs Smith is feeling anxious and overwhelmed by the recent diagnosis. She has no clear treatment plan or appointment to see Oncology and is anxious about the delay in cancer treatment.

- **Mrs Smith is told she has metastatic breast cancer.**
- **Mrs Smith is referred to Oncology but does not see anyone during her admission.**
- **She is referred to the Hospital Palliative Care Team as she has pain and other symptoms.**
- **She is discharged home and receives an appointment for Oncology for 2 weeks time at Cumberland Infirmary Carlisle.**

Mrs Smith feels alone and unsupported. Mrs Smith is anxious about delays in treatment - knowing that time is important - worrying that her cancer is spreading further. Mrs Smith agrees to start some pain killers but is anxious about the implications of a "Palliative Care Referral." She is anxious because of the 2 week wait and also concerned about travelling the 88 miles round trip to the appointment.

Oncology Clinics only held in Carlisle for all patients in Cumbria for new patients.

Palliative Care Service includes services provided by Hospice at Home West Cumbria.

- **The Community Palliative CNS Nurse makes contact and arranges to see Mrs Smith in her own home a few days later and liaises with the GP to commence ongoing pain killers.**
- **The Community Palliative CNS contacts oncology dept to see if this lady can be seen nearer home. However the Oncology dept only hold clinics in Carlisle for new patients.**
- **Mrs Smith becomes increasingly anxious about the Oncology Appointment and her pain resulting in her contacting CHOC several times over the weekend. This results in an admission to WCH.**
- **Hospital Palliative Care Team arrange for Hospice at Home Nurse to travel with Mrs Smith in Ambulance to her Oncology appointment to provide support and give pain meds if needed.**

Mrs Smith is grateful for the support from the Palliative Care Team however remains anxious about the oncology appointment as she does not drive and finds her pain is increased with travel.

Although grateful that the CNS has tried - Mrs Smith is anxious and disappointed that she still has to travel to Carlisle.

Hospital Staff refer to Hospital Palliative Care Team.

Mrs Smith feels relieved that she is not alone although still finds the journey very exhausting and painful.
Mr Jones is a 55 year old gentleman with metastatic bowel cancer whose condition was deteriorating. He lives with his partner at home in Egremont. He has troublesome nausea and vomiting and his symptoms are increasingly difficult to control at home despite intensive input from the GP, District Nurses and Palliative care Team. Mr Jones is reluctant to accept acute admission due to negative past experiences but would agreeable to admission to a Specialist Palliative care bed at WCH (this was also his preferred place of care for End of Life care).

Mr Jones and his family are increasingly struggling at home

- Palliative Care Medical team visit Mr Jones at home as there was no beds on the Specialist Palliative Care unit at WCH and change contents of Syringe driver
- Following day Palliative Care Medical Team visit Mr Jones at home whose condition had deteriorated further, continuing to vomit and becoming dehydrated.
- Palliative Medical Team contact Eden Valley Hospice at Carlisle (44 miles away) who had no beds and Bed Management at West Cumberland Hospital who describe lengthy waits in A & E for Acute beds and no available Community Hospital Beds
- Palliative Medical Team left with no other choice but to provide additional input at home including increased District nurse visits, right time support from Hospice at Home West Cumbria and arrange for fluids to be given at home and Home Oxygen and raise with primary care team

Mr Jones was happy that he was able to have this support at home and avoid an acute admission. Although disappointed that no bed was available on the Palliative Care Unit
Mr Jones feels so poorly that he will accept admission "anywhere" although still disappointed that still no bed on Palliative Care Unit at WCH
Mr Jones feels too unwell to travel to Eden Valley Hospice or to wait in A & E at WCH. Reluctantly he chooses to stay at home
Mr Jones grateful for the support at home but would have preferred an admission to a Palliative care bed

Following the weekend

- Specialist Palliative Care Unit at West Cumberland only had 4 beds and requests for admission often exceed capacity
- Palliative Medical Team review Mr Jones at home after the weekend.
- No Palliative Care beds available. Family reaches crisis point and are unable to manage at home even with the additional support
- Acute Trust Admission arranged by Palliative Care Medical Team as there were no Palliative Care Unit beds and no Community hospital beds available
- After 48 hours bed becomes available on Specialist Palliative care unit at WCH and Palliative Medical Team arrange to transfer Mr Jones to his Preferred place of Care

Mr Jones feels slightly better with the additional fluids and change in syringe driver. Family struggling to manage despite increased support. Mr Jones requesting admission
Family tired and unable to continue to support Mr Jones to stay at home and are becoming increasingly distressed at his deteriorating situation. They are aware his preference at end of Life is to be admitted to the Specialist Palliative care unit at West Cumberland Hospital
Mr Jones reluctantly accepts acute admission as he feels that he has no other choice. Feels too exhausted and unwell to engage with admitting medical team
Mr Jones relieved to be finally where he wants to be, and feels safe and supported. Mr Jones's family at relieved and happy that he is well cared for and they have unrestricted visiting facility.
Mr Brown is an 80 year old gentleman who lives with wife and daughter in West Cumbria. He has metastatic prostate cancer and is known to have widespread bone secondaries. He is well known to his GP and Palliative Care Community CNS. He also sees the Oncology Consultant in clinic.

**Suspected Spinal Cord Compression is an Oncology emergency**

- **Mr Brown’s daughter contacts the GP** surgery concerned about her father’s increasing back pain and reduced mobility and requests a home visit. She also leaves a message for the Palliative CNS as she is unsure who to contact.
- **Palliative CNS contacts Mr Brown’s daughter** and is immediately concerned about the symptoms. She liaises with the GP and arranges to accompany the GP on an urgent home visit.
- **GP and Palliative CNS visit** and are concerned about possible spinal cord compression. They are unclear on the best way to arrange urgent investigation as Mr Brown is reluctant to be admitted to hospital as his wife has dementia and he is her main carer.
- **GP contacts Palliative Care Consultant** for advice who suggests starting high dose steroids and liaising with Oncology Consultant to arrange urgent MRI (and if necessary radiotherapy given at Carlisle). However the Oncology Consultant is on holiday and there is no covering colleague available. GP then arranges an acute admission but is unsure which hospital to admit to.

- **Mr Brown’s daughter is unsure if she should be “bothering anyone” with her concerns.**
- **Mr Brown’s daughter is reassured that she has was justified in contacting the GP and Palliative CNS** and happy that a home visit has been arranged.
- **Mr Brown is now anxious regarding his own health as he is his wife’s main carer.**
- **Mr Brown very upset and anxious about leaving his wife and worried he will be admitted to Carlisle which would cause problems for his daughter relating to visiting and care of his wife**

**Shortage of Adult social Care and Nursing Home places**

- **Mr Brown is admitted to West Cumberland Hospital** as there are no available beds at Carlisle. He has urgent MRI scan which demonstrates spinal cord compression. The medical team liaise with Oncology and neurosurgery regarding his management.
- **Decision is made that Mr Brown is for Palliative treatment only** and he requires urgent radiotherapy. Transport is difficult to organise and so 24 hours later he is transferred to Carlisle Hospital for radiotherapy as a day case. During this time his mobility continues to deteriorate and he remains unable to walk.
- **Mr Brown is referred to the Palliative Care team at West Cumberland Hospital** to facilitate complex discharge planning. A specialist palliative care bed becomes available and he is transferred. Meanwhile his wife has a fall at home and has been to the Cumberland Infirmary with a fractured neck of femur.
- **Mr Brown is seen by the MDT and equipment is in place for discharge but no Social care is available. He is therefore asked to consider a nursing home. Mr Brown’s wife remains at Carlisle as there is no bed available. Mr Brown and his daughter are increasing distressed and referred to Hospice at Home West Cumbria for support and complementary therapy.**

- **Mr Brown although relieved to have had the MRI is devastated that he is now unable to walk. Also he is very worried about his wife and how is daughter is coping.**
- **Mr Brown is feeling very depressed about his situation and desperately missing his wife. He is feeling overwhelmed and concerned about caring for his wife in the future and the burden on his daughter. He is very weepy and overwhelmed.**
- **Mr Brown is relieved he is in a quieter location and discharge is being looked at, however desperately guilty about his wife and daughter. His daughter is exhausted travelling between the 2 hospitals visiting her mother and father.**
- **Mr Brown is very upset that his wife is still in Carlisle as he has not seen her for several weeks. He is feeling helpless and vulnerable and left unsure around his and his wife’s future care plans.**
Mrs Smith lives alone in Workington. Her husband passed away two years ago and since then, Mrs Smith has spent long periods of time alone at home. Her home is becoming extremely cluttered and her GP has identified a potential hoarding issue at a recent home visit. Her GP has also diagnosed her with depression and a high BMI.

Mrs Smith is socially isolated due to her depression and this is resulting in hoarding and is preventing her from accessing support to help with her weight. This is impacting on her overall health and wellbeing, resulting in regular visits to the GP.

- Mrs Smith is isolated and lacks social support to improve her health
- Mrs Smith is at increased risk of falls and infections due to her poor living environment
- Mrs Smith is at increased risk of developing diabetes and musculoskeletal conditions due to her weight
- Mrs Smith’s GP is becoming increasingly frustrated that Mrs Smith’s health is deteriorating despite his best efforts

Mrs Smith’s depression worsens
Mrs Smith says she doesn’t care if she gets ill or has an accident because she could go to hospital and be looked after for a while
Mrs Smith says the aches and pains make her feel even worse
Mrs Smith wants her GP to visit her at home more often

In the future, Health and Wellbeing Coaches (HAWC) are part of integrated Care Communities and can provide flexible 1:1 support to people who have a range of complex health and social wellbeing or lifestyle needs. The GP speaks to the local HAWC and arranges a referral.

- The HAWC spends time with Mrs Smith and supports her to make contact with old friends and a local bereavement group
- The HAWC works with the district council and local third sector partners to help Mrs Smith make improvements to her home
- The HAWC accompanies Mrs Smith to the local weight management group (where she then receives 12 free sessions as part of the weight management programme)
- Mrs Smith’s GP is becoming increasingly frustrated that Mrs Smith’s health is deteriorating despite his best efforts

Mrs Smith’s social networks grow and her mental wellbeing improves
Mrs Smith feels more confident having friends to visit
Mrs Smith loses weight and her wellbeing improves
Mrs Smith has less appointments with her GP, who is pleased to see her health improving