
Report prepared for Hawke's Bay DHB

Patient Journey Workshops

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Journey summary

We summarise the findings from the patient journeys in this section. In particular, we highlight what is working well, what isn't working so well, and some ideas highlighted by the various groups for the future.

We acknowledge the large number of participants and workshop supporters who gave their valuable time and effort to this patient journey series.

1.1 What is working well?

Participants at the workshops often gave positive comments on aspects of the patient journeys. There were services and processes highlighted, often more than once, as examples of what works well in the patient journey.

1.1.1 The staff are dedicated to patient care

Throughout the workshops, participants praised health professionals for their dedication and commitment to patient care:

- Emergency Department (ED) nurses were highlighted as a particular group of staff that do amazing work, with a lot expected of them.
- Kaitakawaenga were often highlighted as being extremely valuable in improving a patient's journey through the system, and ensuring patients were supported and fully informed.

1.1.2 Services are relatively well coordinated in the hospital

Overall, the hospital journey was relatively well coordinated for patients. Staff are aware what their roles are, and they are aware of the current gaps in the system.

ED doctors are able to access Care Insight, where primary care records are held, to help improve patient care. However, participants noted that not all GPs are signed up to it yet, and the system can be clunky to navigate.

Access to certain diagnostics, e.g. CT, was identified as something that works well. Teleradiology in the stroke pathway was identified as a positive initiative aimed at improving patient care.

Participants noted that there is opportunistic immunisation of children on the paediatric ward, an important step towards improving the health of the population.

Participants noted that the acute theatre list on Sunday and the dedicated orthopaedic trauma list helps speed the journey for certain patients.

1.1.3 There are great community services out there

Participants often highlighted the great services that are available in the community, or throughout the whole journey, e.g. Breathe Hawke's Bay and engAGE (and many others).

There will be good things happening in primary care also; but this did not prominently feature in participant feedback in the workshops. A small number of GPs from a relatively narrow cross-section of practices participated in the workshops.

1.2 Key issues identified

A large number of issues were identified in the patient journeys. In this section, we detail the themes that recurred across the journeys.

1.2.1 At the hospital

There are some delays in a patient's journey through the hospital

Participants often identified the need for a 24/7 hospital, which would help speed a patient's journey through the hospital by providing diagnostics and care (e.g. physiotherapy) when they need it (e.g. on the weekend).

Participants identified the duplication of assessments, and the need for patients to tell their story multiple times, as an area that could be improved. While it was acknowledged that the requirement to repeat stories does have clinical value, participants questioned whether it had to happen as often, or to the same extent each time, as it currently does.

Participants noted that patients may have a different experience at the hospital (and indeed in the community), depending on their gender and/or ethnicity. Increased training in cultural competency was often highlighted as a way to stop this happening.

Participants noted a general shortage of allied health workers, e.g. social workers. The limited provision of allied health out-of-hours was often identified as an issue.

Some journeys highlighted the fact that there may be patients that are waiting in ED for longer than they should be, as there are no beds available in the appropriate ward. Patients are also shifted to a ward that may not be the best for them, which may lead to a different care experience.

Communication could be improved – with patients and with each other

Participants noted that communication is a key area for improvement. There are conversations that take place in inappropriate places (e.g. with no privacy). Other times, the patient may not have an appropriate support person with them. Health professionals may not be taking the time to ensure that the patient understands the message, which leads to misunderstandings further down the track.

Workshop participants gave examples of poor communication between hospital staff and general practice. These ranged from not being able to access patient notes, poor discharge summaries, and referrals into hospital lacking important information.

The needs of older people are not being met

The journeys identified that the needs of older people are perhaps not being met as well as they could be. This is highlighted through:

- The focus on the medical issue that brings them into the hospital, not the wider issues, or the causes of the medical issue.
- A lack of delirium management in the hospital, with a lack of pathways.
- Not involving geriatricians as early as possible in the journey, as well as a general lack of geriatricians.

ED design could be improved

Participants in the patient journey workshops identified shortcomings in the current ED design:

- A lack of privacy for both those waiting and those being assessed.
- There are no separate waiting and assessment areas for children.

The ED is often busy and noisy, and taken together with the design issues identified above can create a more stressful environment for patients and their families. For example, for a stroke patient, the noise in ED may be particularly difficult to deal with.

IT improvements needed

Participants often highlighted the difficulty in accessing patient records from outside their location (e.g. accessing hospital records at the GP or vice versa). This creates delays in patient care.

1.2.2 In the community

The transition from hospital to home isn't always clear

Most journeys highlighted the unclear pathways from hospital to community. Participants noted that there were excellent community services out there, but not everyone is aware of them or knows how to access them. There are also some gaps in community services, e.g. for youth, or for pain.

Discharge summaries were often identified as an area for improvement. The summaries are often incomplete or incorrect in some instances.

Multiple points where a patient may be lost in the journey

There are multiple points where a patient might get lost in their journey. Some of these points occur at the hospital, e.g. the waiting times at ED mean some patients may leave. However, the health sector needs to give thought to the destinations for vulnerable people after they leave the hospital and how to make it as easy as possible for patients to attend follow-up appointments. Currently there may be little flexibility for patients to choose their preferred time. Some patients may struggle with transport or other issues.

Patient access and health literacy could be improved

There is poorer access to certain services if the patient is not centrally based. Participants often noted that there might be barriers to GP access. This isn't just about the cost, it may be that GPs aren't accepting patients, or patients are unable to get to the GP when the GP is open, or the GP might not have any appointments available that suit the patient. Additionally, patients might not be aware that it is free for certain age groups to visit the GP, or if the household has debt with the practice, they may not want to visit even though it will be free for the child. Patients might also struggle to find money to fill prescriptions.

Health literacy was highlighted as an important factor in every journey. Sometimes health information and patient education is not provided in a way that allows patients and their wider whānau to understand the condition and empowers them to manage at home. This can prevent patients from accessing care at the right time. They may turn up to ED with deterioration in their condition that could have been prevented by appropriate management at home, with good GP support.

1.3 The future state

1.3.1 Hospital processes

Workforce needs will change

A focus on workforce planning, including recruitment, retention and training will be needed to support future demand, which is likely to be based around different patient needs.

Allied health services will require significant focus and further investment if they are to perform their critical role in keeping people out of hospital (avoid admission, reduce length of stay and avoid readmission), and well in the community.

Change hospital processes for frail

There is a growing frail elderly population presenting to the hospital, with increasing comorbidities and complex care requirements. The way in which the health sector organises how it delivers medical services in the future, across the health system, will therefore need to reflect this changing pattern of demand.

Getting geriatricians involved in patient care early in the journey is important. This may mean redesigning some pathways, and employing more geriatricians. Delirium management is also an important area for improvement, and a clear pathway should be developed.

Remove duplication of testing and histories

A look at where in a patient's journey there is duplication of either diagnostics or patient history taking is needed to identify where duplication occurs and where it could be cut.

Redesign ED

Participants suggested that the following factors should be taken into account in any future redesign of the Emergency Department:

- More private spaces and noise reduction.

- Separate area for children waiting in ED.
- Places for families waiting for news and updates.

At discharge

Discharge summaries could be improved to help with the transition of patient care into the community. The discharge summary should be clear, correct, and go to the right people at the right time.

A complex discharge role will also help transition the increasing number of patients presenting at the hospital with multiple comorbidities and complex care needs.

IT improvements

Participants often identified the need for one health record that is easy to access for all health professionals (including hospital staff and GPs), and for the patient and their whānau. While there have been improvements in the IT area, e.g. Care Insight allowing ED doctors to access primary care records, these should be built upon with the ultimate end goal of one common health record.

1.3.2 Communication and education

Improving health literacy

Improving the health literacy of patients and whānau was highlighted as incredibly important in every journey. Educating the patient on what their health conditions mean and how to self-manage them is extremely important in ensuring the patient gets the care they need at the appropriate time in their journey. Improving the health literacy of the whole whānau will help improve the patient's care, and will help improve everyone's health.

Improving communication

Looking at the way messages are delivered to patients by health professionals is important. Health professionals need to ensure that the messages are delivered in the right place, at the right time, and are understood first time.

Cultural competency training will help ensure the health professionals are delivering messages in the right way to all patients.

Make every health interaction count

There are a lot of times a person may interact with a health professional. The health sector needs to make sure that every interaction is useful to the patient, whether it is about education or getting the patient in touch with other services they may need, e.g. housing.

There is a lot of downtime in a patient's journey, e.g. while waiting for test results. This time could be used to educate the patient in their health condition, e.g. by providing games for children to play to teach them about asthma.

1.3.3 Prevent patients going to hospital in the first place

Increase the focus on prevention

Stopping the patient getting to the hospital in the first place should be the key focus. This can be done by shifting the focus onto prevention, and looking at a ‘wellness model’ rather than a ‘sickness model’. A person’s health is affected by a wide range of social issues, e.g. housing, and the health sector needs to ensure that these issues are taken care of if the health sector wants their population to be as healthy as they can be.

Shift care out into the community

There are a number of ways that the health sector could shift the balance of care out into the community:

- Shifting the delivery of a greater number of specialist services to community settings (e.g. co-located with primary care), closer to where people live and work.
- Invest more in services for vulnerable people. A focus on the wider social issues will help improve the population’s health.
- Increase the supports available to keep the elderly in their homes such as 24-hour nursing if required, more advanced monitoring and greater use of alarms, and other innovations to reduce hospital and rest home demand.
- A commitment to investing in upstream, preventative services.
- Improved integration between primary care and hospital services, and resourcing time for SMOs to provide support and education to GPs.
- An improved health pathways programme, with input from a range of disciplines and improved integration with existing practice management systems so they become embedded in the local health system.

1. Introduction

1.1 Aim of the patient journey workshops

Patient journey workshops provide an opportunity for health professionals, patients and other stakeholders to identify areas of improvement in the care chain from a patient perspective rather than an organisational perspective. The patient journeys are hypothetical but typical cases. The objectives of the patient journey workshop are:

- To map out the patient journey, and identify where processes or activities are considered to be positive or negative to patient care or flows.
- For each participant to have an opportunity to provide input into the patient journey.
- To gain more awareness of how other clinical and non-clinical staff affect the patient journey.
- To make suggestions about a transformational change to service directions.

1.2 Acknowledgement

We thank the large number of participants and workshop supporters, including patients and District Health Board (DHB) senior management who attended the workshops and gave their valuable time and input.

1.3 Where patient journeys fit in the wider planning process

Patient journeys are one input into the Hawke's Bay Clinical Services Plan. As a whole, the Clinical Services Plan identifies the clinical services and models of care that will be needed to meet the future demand of the population of Hawke's Bay.

It is not limited to hospital-based services, but considers the primary and secondary clinical services delivered within the Hawke's Bay Health System. The Clinical Services Plan underpins long-term financial, capital investment and workforce plans.

2. Approach

Hawke's Bay DHB and Sapere held eleven patient journey workshops over eight sessions from 11 to 22 September 2017.

Table 1 Summary of workshops

	The journey	Date held
A	Stroke	11 September 2017
B	Congestive Heart Failure	11 September 2017
C	Youth Alcohol and Other Drugs	12 September 2017
D	Youth Pregnancy	13 September 2017
E	Fractured Neck of Femur	13 September 2017
F	Inflammatory Arthritis	13 September 2017
G	Tertiary Oncology	20 September 2017
H	Paediatric Asthma	20 September 2017
I	Diabetes and Kidney Disease	21 September 2017
J	Ear Disease	21 September 2017
K	Dementia	22 September 2017

2.1 How are patient journey workshops run?

The patient journey workshops were jointly facilitated by staff from Hawke's Bay DHB and Sapere Research Group. Participants were organised into tables of up to ~15 people to ensure (as far as possible) a balance of views among the various services. Table facilitators were selected from the DHB, to ensure the process was wholly owned and "voiced" by the DHB.

To ensure optimal participation from participants, an informal and low-tech approach was used. The DHB facilitator identified for each table guided participants through the journey. The workshops were divided into two parts – the current state, and the future desired state.

Workshop participants included DHB staff (clinicians and management), representatives from primary care and community organisations, and patient representatives and support people.

Part A – the current state

Groups were asked to track the patient journey in detail from the point of entry to the point of exit of the health service. Each group had butcher's paper drawn as a table with time on the x axis and the setting on the y axis (e.g. hospital or community).

Participants were asked to note the activity in the care chain and the setting (and other relevant details) using colour-coded post-it notes (yellow for an activity, blue for processes that go well, red for issues, and purple for future ideas). The groups worked collaboratively on placing these in order on the templated butcher's paper.

Groups were asked to report back through a series of 'rolling presentations', whereby the second and subsequent groups only raise points that have not been addressed by previous groups.

The resulting representations of the patient journeys in this document, as set out in Appendix 1, are a tidied up copy of what the groups identified on the butcher's paper. It should be noted that some of these journeys were relatively complex and some groups did not complete the entire journey.

Part B – the future state

During the second part of the workshop, groups were asked to identify what they thought an ideal state would look like in the future. The groups were asked to be transformational in their thinking. At the end of this stage, the groups again reported back via rolling presentations.

This material is one input into a wider process of Clinical Services Planning across Hawke's Bay DHB. The description of the current state of patient pathways is based upon the information recorded by participants in the patient journey workshops and has not been subject to further verification. Workshop participants provided their views and experience of the strengths and weaknesses of patient care in good faith, but the material recorded in this process will be subject to further validation and critique as part of the DHB's continuous process of reviewing and improving services.

3. Journey A: Stroke

Pita is a 68 year old Maori male living in Central Hawke’s Bay visits his daughter in Hastings over a long weekend.

He noticed on Sunday he was having difficulty buttering his toast. His daughter also thought his speech had become slurred.

She brings him straight to the ED.

Key reflections



While the journey went relatively smoothly at the hospital, with some workforce shortages particularly around allied health, the transition to the community could be improved.

Participants were not clear about what services were available to the patient in the community. There are a lot of good services available that are perhaps not used as often as they could be. Participants noted that patients are not aware of what will happen once they have been discharged, or of the wait times involved in accessing some of the services.

At the ED



Pita presents to ED with his daughter and after registering at reception is triaged by the RN. His health record is ordered automatically from CHB.

The triage nurse will move him straight to ED or resus where a Code Stroke will be called, and investigations (e.g. CT, bloods, x-rays)/treatment ordered. There will be times where the patient is waiting for test results.

After being seen by the ED Doctor and all investigations complete, a decision will be made about whether to thrombolysed. If he is thrombolysed, he will stay in ED while the treatment is administered.

Ward B2 is notified of the Code Stroke.

! The ED environment is loud and bright. As Pita’s records are off-site in CHB, there will be a delay in accessing them.

! ED nurses are unable to complete a swallow screen.

! There is a great, seamless stroke pathway. However, the pathway isn’t always followed.

👍 Triage by the nurse happens quickly.

👍 Communication in the ED by nursing staff is very good, and they regularly check in with Pita and his family.

👍 Access to CT is good. The telestroke system, which allows specialists at Wellington Hospital to offer after-hours support via video-link to Hawke’s Bay regarding thrombolysis therapy, can result in faster diagnosis and treatment


On the Ward (likely Ward B2)





Pita is admitted to ward B2 where he will undergo specialty ward assessments – SLT, OT, PT, CNS within 24-48 hours. There is always a senior nurse in B2 that can do a swallow screen. Depending on what time he arrives on the ward, he may not be seen by a consultant until the next day.



Pita will receive daily therapy (Monday to Friday).

MDT and IDT meetings occur and a referral to AT&R will be made when the team thinks he is ready.

 The transfer from ED to Ward B2 is very good. However, there isn't always a bed available immediately in B2, leading to inappropriate use of an HDU or ED bed while waiting.

 Family is involved in the decision making, however, communication drops off from the level it was at in ED. By now, John is tired of telling his story over and over again

 Active rehab only starts on week days. There is a shortage of Allied Health staff e.g. speech therapy, especially on weekends and public holidays. There can also be delays in SMO review, and it is not always clear who is in charge of John's care.

 There can be a long wait on B2 for AT&R review and acceptance.
 If Pita is discharged home from B2, the discharge process is not as comprehensive as the AT&R discharge.

At AT&R





Once transferred to AT&R, Pita will undergo assessments by OT, physio, RN within 24 hours.

A family discussion will take place for Pita's discharge, and a package of care (e.g. showering, housework) will be sorted for when he goes home.

The Stroke Foundation will visit him in hospital and he may be referred to the Kaitakawaenga, if not already referred earlier in his journey.

Discharge planning commences on admission to AT&R and a discharge summary will be created when he is discharged. Pita will be provided with the right equipment to go home with.

 Pita may not see an AT&R consultant until several days after his admission. Certain Allied Health resources are also limited in AT&R, for example, speech therapy and OT.


 The discharge summaries are not always clear and do not always say who needs to do what.


At home




At home, Pita will have home visits by the OT, and will have a NASC assessment. The Stroke Foundation may also visit him at home. He will also attend outpatient treatment, such as physiotherapy.

He will attend follow-up appointments with his GP, and the CNS stroke will follow-up also.

 There is a lack of communications with the patient about what happened post-discharge.

 There is a cost factor involved for John with his GP appointments, and transport to the GP and other outpatient appointments. Pita may also experience waits for outpatient therapy such as SLT and physiotherapy.

 While there are good Maori Health provider packages available, there is a lack of knowledge in the community about these.

 As Pita lives in Central Hawke's Bay, there are fewer community services available to him.

3.1 How to improve

System changes

Participants identified a need for stroke prevention. This would involve improving access for high risk patients, for example, having health assessments in various settings, including the workplace, or providing a funded annual appointment at the GP. The health sector needs to focus on empowering the patient by improving their health literacy to allow them to take self-responsibility for their own health.

The health sector needs to focus on the transition to the community, with clear pathways and knowledge on the services that are available to the patient. Improved communication with the patient so they know what is happening, and how long they have to wait for services, is needed.

Incremental changes

- “Make every health interaction count” – there are a lot of contacts between health professionals and patients in both primary and secondary care. We could use these contacts better, particularly if there is downtime (e.g. waiting for tests), to help educate the patient.
- A welcome pack for patients on arrival on ward B2.
- MDTs seven days a week.
- More allied health staff.
- All ED RNs trained in swallow screen.
- Create a health services directory so everyone is aware of all the services on offer.
- Stroke rehabilitation classes in the community.

4. Journey B: Congestive Heart Failure

Wiremu is a 60 year old Maori male, heavy smoker, type II diabetic (controlled), with known CHF.

He lives independently in Hastings. He gets breathless easily (e.g. walking to the letterbox) and has become increasingly tired.

He has a very supportive family and two of his children live locally and visit daily. His daughter visits one Friday and is concerned as he appears more breathless than usual. She notices that he has developed a dry, hacking cough. She phones for an ambulance and accompanies him to ED.

Key reflections



Participants stated that health literacy is very important in this journey. The ultimate goal is good self-management of the condition, to keep the patient out of the hospital for as long as possible. The health sector need more education for the patient so they know what things mean e.g. change in weight, and what to do when they notice changes.

An important part of patient education is explaining and ensuring they understand the aetiology of their disease, i.e. why this has happened to them.

The value of heart failure rehabilitation and exercise programmes was noted (not currently available in Hawke's Bay), as was the need for more nurse specialist resource working out in the community and with primary care.

Ambulance and at the ED



The ambulance will contact ED ahead of time with a status code depending on how serious Wiremu's condition is. They may put an IV line in.

On arrival at ED, he will be triaged by an RN and then put in a bed space. His daughter will register him at reception.

Wiremu will undergo observations and investigations ordered by an RN, including bloods and an ECG. A chest x-ray would need to be ordered by a doctor.

A Care Insight review will be undertaken by the RN or a doctor to see what medications he is on.

Wiremu will then be seen by the ED doctor who will assess him and begin treatment. A referral will be made to Medicine who will further review him and make a decision on where he needs to go.

A bed request will be made electronically.



Wiremu can become a St John's member to save money on ambulance transports.



The triage process happens very quickly and nurses are supportive and caring.



Family get to stay with the patient in ED.



The ED volunteers are great.



Wiremu has family close by who know that is normal for him and can detect a deterioration.



The electronic bed request is fast and visible to anyone looking at the ED screen.



There will be a lot of waiting time between tests, seeing the doctor, being referred to Medicine etc. There is sometimes little explanation of what is happening and why/how long they need to wait.



Wiremu will be feeling like he is a nuisance, wondering why it is happening again, and will be reluctant to be there.



The ED environment does not have much privacy.



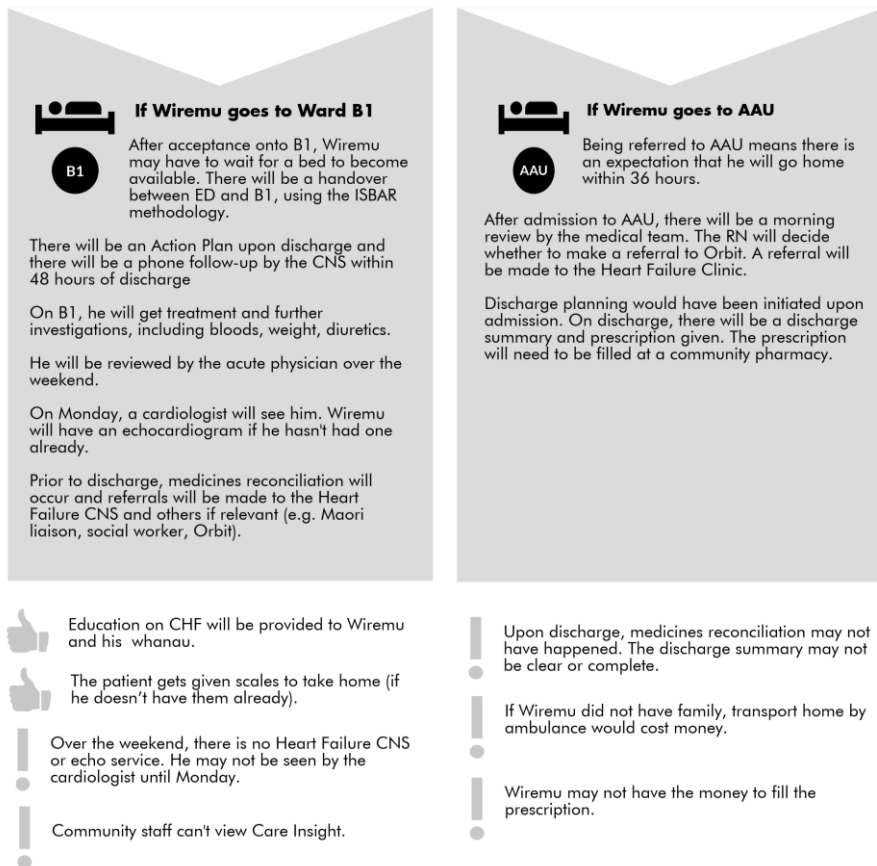
There may be duplication of assessment as Wiremu is passed from doctor to doctor.



There is food available for the patient in ED. However, there are limited/no food options for his family.



Nurses can't necessarily order a chest x-ray and may have to wait for a junior doctor to sign the order.



4.1 How to improve

System changes

Participants identified a need for increased specialist resources to help improve patient education and care. For example:

- a heart failure rehabilitation programme
- more heart failure CNSs, working together with primary care.

A focus on whānau wellness was also identified by participants as important. Focussing services on the needs of the whānau, rather than specific illnesses, can improve the health literacy of the entire whānau. NGO providers are useful to support this work.

Incremental changes

- Every CHF patient gets a Personal Action Plan and diary to help manage their condition.
- Nurse prescribers to allow more frusemide treatment in the community.
- Improved access to psychologists and dieticians for patient behaviours and lifestyles.
- More heart failure CNS resource.
- Improved smoking cessation education.
- Improved linkages with NGOs so people can make the most of the services that are on offer.

5. Journey C: Youth Alcohol and Other Drugs

Hoani is a 17 year old Maori male picked up by Police with drug related psychosis.

Key reflections



In an environment of increasing demand for mental health services, the key reflection here was one of a fragmented journey. There were few services available for youth, especially locally-provided services.

Police appear to be organised and in some cases very experienced in dealing with acute mental health situations. However, participants described examples where young people are treated differently depending on their gender or ethnicity. This applies to the hospital system as well.

Young people that are admitted as inpatients in the Hawke's Bay are not in a youth specific environment and youth specific AOD services are lacking in the community.

Primary care struggles with increasing mental health demands and needs more support and upskilling to manage this. Further, services in the community need to reflect the spontaneous nature of how young people tend to access them rather than appointment based systems that miss opportunities to engage.

It was noted that adverse childhood experiences have a profound impact on mental illness and addiction as young people grow up.

In the community



A member of the public will call the police. The police will arrive on scene, assess the risk, and depending on the situation, may either take him to the cells (e.g. if he is violent), or straight to ED.

If the person is not at imminent risk to themselves police would liaise with EMHS and call the police medical officer on duty. At night it is more likely to be taken to ED for assessment; that is what happens for Hoani.

Police will liaise with EMHS prior to bring him to ED, and EMHS will often meet them in ED. It is possible to go direct to the inpatient mental health unit, but most patients go to ED.

EMHS will call the kaitakawaenga who will come to ED. Police or the kaitakawaenga will phone the family.



More experienced officers know how to de-escalate the situation.



If Hoani goes to the cells, this may worsen his condition.



The experience can be different depending on ethnicity or gender.



Youth can react negatively to police

At the ED



The patient will be triaged by a nurse and then may need to wait before they are assessed by EMHS. EMHS will likely call the on-call doctor to provide further assessment and treatment.

ED clinicians will assess Hoani for any physical health needs. The order depends on how acute the medical vs mental issues are.

The Kaitakawaenga and/or security will sit with him and his family.

At this point, a decision will be made about whether to place the patient under the Mental Health Act. This will be discussed with the family, and the consequences of the choices explained.

A decision will be made on where to place the patient. A plan will be made with the patient, EMHS and whanau. The duty manager will coordinate the bed (if needed).



Kaitakawaenga are fantastic, and may know the patient and family.



There are specially trained security and staff. Ethnicity is a great de-escalation tool.



There is a whanau room available.



There may be long periods of waiting, which may 'freak out' the patient. The experience can differ with ethnicity.



The ED is not the right place to be waiting. Assessment rooms are cramped and may not be private.



EMHS may have to prioritise their workload due to limited staff available, especially after hours. This may lead to further delays.



The language used may not be understood by the patient.



Psychosis may be misdiagnosed as drunk and disorderly.



Where to from here?

Assuming that he does not have any other medical issues that require managing, there are three possible places he might go.

To the Rangatahi Regional Service for youth (Wellington):
He will be transferred to Wellington to the youth unit. He will be assessed and treated. His whanau will be involved in discharge planning. After treatment, he will be discharged back to Hawke's Bay with a "Go To Plan" and package of care. He may go to the step down facility 'Emerge'.

To Nga Ra Rakau (Hawke's Bay):
Nga Ra Rakau is the mental health inpatient unit. He will stay there with a 1:1 watch because of his age (under 18). There will be whanau meetings, and he will attend therapy and get medication. Hoani will be assessed daily by a psychiatrist (or twice daily). There will be a discharge plan created, with input from kaitakawaenga and whanau.

Discharged from ED:
He may be discharged straight from ED. He will be discharged with a referral to CAFS, and possibly a script for an antipsychotic. However, with psychosis, it is more likely there will be an admission.



Rangatahi Regional Service may not have capacity to take him. As the unit is in Wellington, his whanau may not be able to go with him (they are allowed to, but they may have to work or look after other children etc).



There is no youth unit in Hawke's Bay.



There can be quite a process to agree the discharge plan with the whanau. There may be resistance to being responsible for a part of the plan.



The step down facility, Emerge, may not have capacity to take him.



Whanau Tahi is an innovation by the mental health service. It is an electronic, living plan that care providers with access to ECA can view.



At home

In all cases, he will get a CAFS referral. CAFS will allocate a key worker. The key worker will figure out the plan and sort any issues by looking at his needs.

The GP will get involved with his followup.



There are no kaupapa Maori community alcohol and drug services for youth.



He may not have a GP. His family may not be able to afford the cost of treatment and followup.



No services are available to address the issues of the whole family.



Counsellors may fail to build rapport with a young person, e.g. if they find it difficult to understand someone from another culture.



A lot of youth groups are church-led and may not be appropriate for all youth.



Some schools are very good at delivering the drug and alcohol curriculum whereas others aren't.

5.1 How to improve

System changes

Any changes should be co-designed with youth and whānau to ensure the service is appropriate for them, and will be used. There are examples of For Youth By Youth programmes being delivered in other parts of the country, and these are being investigated by the Hawke's Bay youth council. Solutions should serve the whole whānau, not just the consumer. As an example of what is appropriate, participants noted that the current appointment-based system does not work for youth, who prefer a drop-in service.

Participants identified the need to up skill primary care to more confidently deal with mild to moderate mental health issues, and a move towards a more behaviourist approach. An overall increase in mental health professionals, both in the hospital and in the community, was desired by participants.

A dedicated adolescent mental health unit in Hawke's Bay, to avoid travel to Wellington, was identified as a solution by participants. Removing the mental health process from ED was also highlighted as important.

Work to remove the current stigma around mental health, not just for youth, would help improve the chances of people seeking help at earlier stages. Fostering a culture where mental health becomes an everyday conversation among youth and whānau is important to help remove the stigma.

Incremental changes

- Enough dedicated space in ED (or elsewhere) for assessment. Appropriate spaces may be full at the time, so more are needed.
- Increasing the diversity of youth groups in the community, and improving coordination between them and other services.
- Increasing school counsellor FTEs.
- Space/place for youth to gravitate to in their community.

6. Journey D: Youth Pregnancy

Ana is a 17 year old Maori woman who is 6 months pregnant. She has not gone to the GP to confirm the pregnancy and has no Lead Maternity Carer.

She has been smoking since she was 12. She lives at home with her parents and her father is violent towards her mother. She is also experiencing violence from her boyfriend.

She presents to ED with significant bruising and is worried about her baby.

Key reflections



The journey for Ana is set against a background of considerable social complexity, which may not always be well understood by the people interacting with her along the way. She may feel embarrassed or judged by health professionals. It was noted that initial contacts can "make or break" the system we expect a young woman and her whanau to navigate through.

There is a balance to be struck between maximising the opportunity to deliver other education, screening, or interventions; and recognising what the most important issue of the moment is for a vulnerable young woman who is likely to be focussed solely on the wellbeing of her baby.

A woman experiencing violence may choose to stay with her partner, and in these cases it is even more important to reserve judgment and focus on how to keep her as safe as possible. It is important to listen to what the woman wants the whole way along the journey.

Staff working with vulnerable whanau are dedicated and praised by their colleagues, however despite best intentions sometimes connections can fall down if there is a lack of integration or communication between different parts of the system. In some cases, specific services such as youth specific safe housing, are not available.



At the ED

Ana will self-present to ED and will register with the front desk. She will be triaged by a nurse and then will be in the waiting room until she is seen by an RN in the department.

The RN will confirm the pregnancy, conduct a smokefree screen and ask about family violence. A Safety Plan will be discussed with Ana and the social worker will be contacted. Ana will then be assessed by a junior doctor. A scan will be booked and links made with the social worker and/or kaitakawaenga.

From ED, Ana may be sent home, or she may be referred to Ata Rangi (the hospital's specialist maternity facility).

! There is a lack of privacy in the ED for conversations. A lot of triaging and screening can take place in the waiting room which is inappropriate.

! The ED is not set up to address wider social issues, and is very medically focussed. ED nurses, particularly in after hours, have a very long list of social things they need to deal with, but may not have the time so issues may be missed. The level of social support someone gets may be dependent on how busy the nurse, or the wider ED, is.

! Ana may feel judged by hospital staff.

! The significant waiting times may mean that Ana leaves altogether, or periodically for a smoke.


! Social workers are not available after hours, and are not always informed. There is a kaitakawaenga on-call, but they are not always contacted.

👍 When a kaitakawaenga is called, they provide excellent support to the patient.

👍 'Did not waits' at ED are followed up by telephone.

👍 Family violence screening is increasing in ED and AAU.

If referred to Ata Rangi











A referral to Ata Rangi will be made, and Ana will arrive. From here she will undergo a midwife assessment and a doctor's assessment. She will be referred to an LMC, to ultrasound, and a GP (if she doesn't have one).


If not done earlier, a family violence screen, social worker referral and smokefree referral will be made. She will be referred to the Maternal Wellbeing and Child Protection Programme.

She may also be referred to Te Taiwhenua O Heretaunga (TTOH) which runs a teen parent service.

Prior to discharge, there will be safety planning for Ana, so she knows what to do if it happens again.







-  There is an incentivised smokefree programme.
-  By the time Ana arrives at Ata Rangi, she would have had to repeat her story multiple times.
-  There may be poor information on the discharge summary. Ana may not understand her discharge plan.
-  Confidentiality of stored information shared between providers can be an issue.
-  The community midwives are brilliant and persevere to reach women.
-  There is no clear community pathway from discharge.
-  Ana is unable to get an ultrasound while at Ata Rangi, so needs to get it another time.
-  How does Ana get home once she is discharged?

At home



Once back home, the midwife and the Maternal Wellbeing and Child Protection Programme (MWCP) will try to get in contact with Ana. There will be a MWCP MDT discussion about Ana.

If Ana does connect with the midwife, the midwife will make relevant referrals and discuss the situation with the patient. There will be routine ante-natal followup.

-  There are no residential services providing a safe house for under 18s.
-  Ana may not have a GP.
-  There can be a disconnect between providers and referrals are not always acknowledged. Poor integration between IT systems is a barrier.
-  Ana may not engage with the midwife and GP in the community. She may not answer calls from healthcare services.
-  Ana may struggle with transport to get to any appointments.
-  TTOH provide a wrap-around service involving whanau.

6.1 How to improve

System changes

Dealing with the ‘causes of the causes’ is a long-term challenge, that recognises the impact and responds to trauma in whānau and adverse experiences during childhood. A meaningful co-design process would seek to ensure investment in services offers choices for women, and that any door is the right door.

Improving integration between primary and community, and hospital services is critical, including the way information flows across.

Increasing access to services out of hours means that people can receive services when they want to access them. Social workers available in ED 24/7 could manage complex social circumstances that ED staff may be reluctant or ill-equipped to deal with.

Incremental changes

- Double check patient contacts at ED to ensure we have the correct phone number and email address.
- Private rooms for consultations at ED.
- Enabling staff to focus more on the social issues.
- Ensure consistency at the first point of contact (i.e. pathways). No matter where you go, you should get the same help and information. It is important that young women and girls know where to go and not be afraid to approach services.
- Navigators can help people negotiate their way through the system. There are some navigators currently, such as the Pacific navigators, or Choices, which works with clients of its own midwives.
- Healthy relationships education programmes need to include boys as well as girls.

7. Journey E: Fractured Neck of Femur

Joy is an 85 year old woman, living alone. Lives independently and has not been formally diagnosed with any memory impairment, although family members (that live outside Hawkes Bay) have noticed that she has become increasingly forgetful since her husband died a year prior.

A concerned neighbour found her on the kitchen floor on Saturday morning after noticing that her curtains had not been pulled back. It appears she may have been there all night. An ambulance was called and a fractured neck of femur was suspected clinically. She had a fractured wrist a few years earlier.

Key reflections



The journey described doesn't focus on why she fell; it is aimed at treating the fracture. However, her fracture isn't the diagnosis, it is the symptom – the diagnosis is frailty. The focus should have been on preventing her falling in the first place.

The in-hospital pathway is working well, if it is followed. However there are resource constraints, particularly around allied health on the weekends, and orthogeriatricians overall. Delirium management is a key part of the journey that appears to be lacking.






At the ED






The neighbour will call an ambulance that will arrive at the scene, assess Joy, and provide pain relief.

At the ED, there will be a handover between the ambulance and the ED staff. The paramedics will have brought in her medications. Joy will be triaged, moved into ED and then assessed by a doctor. Diagnostics will be run e.g. x-rays, and she will be warmed, cleaned and hydrated.

Once fractured neck of femur is confirmed via x-ray, she will be referred to orthopaedics and the NOF pathway will be initiated. The pathway includes analgesia, fluids, femoral nerve block and food.

-  Paramedics are good at giving pain relief and are generally prompt in their response.
-  There is good access to x-ray, and in close proximity. Communication with radiology is good.
-  At the ED, the patient may be confused or delirious, so will not be a good historian.
-  The ED is chaotic and not an 'older-friendly' environment.
-  The orthopaedic registrar on call will be covering both ED and theatre, so there may be delays.

-  Sometimes the NOF pathway isn't followed completely. ED clinicians may not feel confident administering the femoral nerve block, leading to possible delays while waiting for an orthopaedic registrar.
-  Joy may need to wait, depending on how busy the ED is. There are limited pressure-relieving mattresses in ED.
-  There is no definite process for keeping the patient informed.



Ward & OT

The patient will be booked on the acute theatre list and transferred to the ward. The process will be explained to Joy and her family.

Consent will be obtained and anaesthetic review. Acute surgeries are booked after the elective surgeries, so it is likely her surgery will be in the afternoon. The theatre runs a surgical safety checklist.

Post-surgery she will be in the ward for recovery. The physio will get her up on day 1 and an x-ray will be taken day 1 post-op. At the MDT, they will identify any further need to rehab, and a decision will be made about where Joy goes. Discharge planning will be finalised, and a referral made to ACC (if not done earlier in ED).



There is a dietician on the ward to help with nutrition.



Having a Sunday theatre list is a good thing.



There may be a wait for a bed in the ward. There is no anaesthetic review on the weekend, and it is sometimes difficult to access some diagnostics, e.g. echo, on the weekend.



Due to possible delirium, does the patient have the capacity to consent to surgery?



There is an orthopaedic trauma meeting review with a good clinical and cultural mix. However, there are no 'big picture' discussions regarding ceilings of care.



If the operation is cancelled (possibly due to theatre capacity issues), if the patient was nil by mouth, this may lead to further deconditioning.



There is no pre-op optimisation of geriatric issues such as delirium and polypharmacy.



60% of NOF patients have a period of delirium post-surgery. In recovery, there is no delirium diagnosis and management. Osteoporosis management is often overlooked.



There is no occupational therapy on the weekend.



Discharged straight home

Referrals will be made to NASC/engAGE (one referral point).

Referrals to DN, NGOs, physio will be made. A package of care (ACC/NASC) will be organised, initially for 6 weeks.

Joy will be transported home.



Discharged to AT&R

The MDT may have identified that Joy needs further rehab, so she is referred to AT&R. Upon acceptance and transfer to AT&R, she will undergo a nurse/medical/MDT assessment and goal setting. She will receive therapy on the ward.

There may be a possible home visit, and she will be issued equipment. Referrals for ACC support and a medical alarm will be made. Referral to NASC will also be made.

Joy will be discharged and then followed up in the community from either engAGE or a community physio. She will receive a home-based falls prevention assessment.

She will be followed up by the fracture liaison service and will receive an interRAL assessment within 6 weeks. She will also be follow-up by the orthopaedic CNS.



Discharged to a step-down facility

Joy may be discharged to a step-down facility. From there, she will get a medication review and daily therapy during the week.

There will be staged home visits and a weekly GP review and MDT with GP input.

There will be a family meeting to plan her discharge home, and a home environment assessment. Referral to other community services e.g. Enliven, will be made.

Family or engAGE staff will transport Joy home, and engAGE will continue at home.

The GP will follow-up, and the orthopaedic CNS will also follow-up.

- There will be no falls cause assessment for Joy at home.
- She may have been discharged too early, with delirium not acknowledged.
- Contracts and agency staffing issues may delay the start of her care at home.
- If transported home in an ambulance, Joy may not be aware that she may have to pay for this service.
- There may be a cost barrier and transport issues for Joy to visit her GP for followup.
- There may be a wait for an AT&R bed. This may lead to further deconditioning for Joy.
- Once at AT&R, there is no therapy on the weekends, and it is possible that Joy will actually receive less rehab than when she was on ward B3.
- At home, there is a lack of clarity re engAGE vs community physio.
- Agency staff may not show up for support at home.
- If Joy lived in Waipukurau or Wairoa, there would be no engAGE service.
- In the facility, there is no therapy on the weekend.
- The facility will operate an IDT approach, leading to less confusion.
- There may be a cost barrier and transport issues for Joy to visit her GP.

7.1 How to improve

System changes

Within the hospital, develop a delirium pathway that starts in ED. A geriatrician could have oversight of the patient through the journey (additional geriatricians are needed). To remove duplication of tests, the patient should undergo one comprehensive assessment throughout their entire journey.

In the community, enhanced falls prevention services at home are needed to prevent fractured neck of femurs from happening in the first place. Improved fracture liaison services would also help e.g. intervening at a time when someone breaks a wrist, as a way to prevent a more serious fall from occurring.

Incremental changes

- More pressure-relieving mattresses.
- Increased access to medical alarms.
- More options for transport home, and to other appointments.
- Have a clipboard in hospital with the patient event information, to minimise the patient needing to repeat their story over and over.

8. Journey F: Inflammatory Arthritis

Alice is in her mid-30s and is diagnosed with inflammatory arthritis. She is currently off work and is having difficulty accessing Rheumatology, Orthopaedics, Radiology for injections.

She has one three year old child, and would like to have another child soon.

Key reflections



The main reflection in this journey is one of access to specialist services. Referrals to the rheumatology and orthopaedic services are often declined, and the services are under strain from high demand and a lack of resources.

Alice has a life-long condition, and the health sector needs to make it as easy as possible to access the care she needs, when she needs it, over the course of her life.

The diagnosis



Alice's diagnosis would have been made by her GP, who would prescribe her medications and sign her off work.

Her GP will make referrals to multiple services, including physiotherapy, hand therapy, NASC, WINZ, the Arthritis Society and a specialist Rheumatologist.

! Alice is worried about her employment status and may be feeling adverse effects from the medication. She may be suffering loss of income, as she may have used up her sick leave and the condition is not covered under ACC. Her medications and trips to the GP are costing her money.

! Referrals to the Arthritis Society are not always made and often the patient finds out about the Society on their own.



Under specialist care

The referral to the Rheumatologist will be triaged and prioritised by the Rheumatology Service at the hospital. However, patients are often declined for an FSA. If this occurs, the GP will need to re-refer Alice to the Rheumatologist using a 'change in circumstances' on the referral form.

! Patients are sometimes declined for an FSA in rheumatology. There is up to a 4 month wait for an FSA, once it is accepted by the service.



Treatment options: Steroid injections

Steroid injections can be performed by the GP, radiologist or rheumatologist – depending on the location of the injection and training of the health professional.

If Alice needs a steroid injection that has to be performed by the rheumatologist or radiologist, this will need to be organised through the specialist service at the hospital. There will be a wait involved.

- ! Steroid injections affect joints and may not work for everyone.
- Not all GPs perform steroid injections.



Treatment options: Medications

Analgesics/anti-inflammatories will be prescribed for day-to-day management of her pain.

Disease-modifying anti-rheumatic drugs (DMARDs) will also be prescribed and Alice will be monitored. If the DMARD Alice is on becomes ineffective, she may be switched to a new one – creating a medication loop as new DMARDs are tried out once current ones stop working.

- ! Alice will be worrying about how the drugs will affect her fertility.



Long term management

A Return to Work plan will be created by the GP.

Her wait for an OT assessment may be months.

- ! At this point, Alice may be under financial strain if she has taken extended time off work.
- ! As the disease progresses, she may experience a decrease in quality of life and anxiety/depression over her body image.



If Alice needs a joint replacement

A referral to the orthopaedic service will be made by Alice's GP or Rheumatologist. If accepted, she will have an FSA with the orthopaedic surgeon. The surgeon will score Alice using criteria to see if she meets the threshold for surgery. If she does, she will be put on the waiting list for surgery.

Prior to undergoing surgery, she will attend "Joint School" where she will meet staff on the ward, have a plan for discharge and get education about what is ahead.

Her joint replacement may be postponed due to acute surgery taking precedence in the theatres. After her surgery, she will receive rehab on the ward prior to being discharged home.

- ! 2/3 of patients are declined an orthopaedic FSA. 1/2 of patients who get an FSA are declined surgery. This means that only 1/6 of those referred for an FSA to get a joint replacement actually end up getting surgery each year.
- 👍 The Joint School initiative has led to shorter lengths of stay. It helps build confidence in patients.

8.1 How to improve

System changes

Arthritis is a life-long condition, and services need to be organised with that in mind.

Once a patient is under the care of the rheumatology service, participants questioned whether the follow-ups done by the rheumatologist were actually necessary, or were actually performed as a way of keeping the patient in the system. If the patient were discharged from the service, the GP would need to refer the patient back in all over again. If a patient had a well-constructed treatment plan, then they could be managed mainly by the GP.

Participants referred to the service delivery in Nelson Marlborough as a means of moving specialist services to primary care. In Nelson Marlborough, they have implemented a model of care consisting of GP-based clinics (served by interested GPSIs [GP's with a Special Interest]), overseen by a private Rheumatologist offering advice at point-of care.

At a higher level than rheumatoid arthritis, participants wondered whether we are funding the right types of surgery. Obese patients are receiving joint replacements that they may not have needed if they had bariatric surgery earlier to reduce the strain on the joints.

Incremental changes

- Participants highlighted the lack of pathways for rheumatoid arthritis. There is no local clinical pathway or Map of Medicine pathway.
- On the referral form to the Rheumatology service, add a box saying “refer to Arthritis Society (with patient consent)”. Not all patients are referred to the Society, which is able to provide a lot of help.
- Once a patient is discharged from the Rheumatology service, they need to be referred back in. Participants suggested a quicker pathway is created back into the Rheumatology service i.e. a referral for a follow-up, not an FSA. This may help stop unnecessary follow-ups that may happen in the rheumatology service just to keep the patient in the system.
- Increase specialist resources trained to deal with arthritis e.g. GPSIs, Nurse Practitioners, Clinical Nurse Specialists, and Rheumatologists.

9. Journey G: Tertiary Oncology

Kate lives in Hawke’s Bay and was diagnosed with a brain tumour. She will undergo surgery in Wellington and radiation therapy in Palmerston North.

Key reflections



In this journey, patients highlighted the fact they needed to advocate for themselves in order to get all the treatment options available to them, and to drive the journey forward. However, not everyone will be able to do this, possibly due to poor health literacy or a lack of confidence. Patients should not need to be health literate, well-resourced and well-researched in order to get the best possible care.

Another key reflection in this journey was that clear communication of messages and processes is essential. Good processes around ensuring the patient understands the message given to them are needed, including:

- not using medical jargon
- ensuring the message is delivered in an appropriate and private space
- ensuring a support person is present, if needed
- thinking about how the patient leaves after hearing the news
- ensuring an interpreter is present, if the need is identified
- providing the next steps and the timeframes associated with those steps. It is not sufficient to give news, and not be able to tell the patient what is going to happen next.

Additionally, wait times that are communicated to the patient need to be kept. The waiting is one of the hardest parts for a cancer patient, so ensuring timeframes are clear and kept to is essential. If there is a deviation from the wait time, this should be communicated to the patient, with reasons why, and a new timeframe given.

In Hawke's Bay



HB

Kate will experience symptoms and visit her GP. The GP will refer Kate for investigations, such as a CT scan. Kate may be showing red flags, and the GP and radiologist will discuss her over the phone.

Kate will be booked for a CT scan. She will undergo the scan and the results will be reported to the GP. The GP has a system to check that tests have been done.

Kate will then be referred for specialist review.



There is good GP access to CT and radiologists are available by phone to discuss patients.



There is an urgent finding procedure in radiology, and this will be phoned through to the GP. CTs are generally reported the same day.



The GP referral for investigations might be poor quality, and may not state there is a high suspicion of cancer. This means the patient isn't flagged as on the 'Faster Cancer Treatment' pathway, and there may be delays in accessing tests.



The GP appointment time may be too short, and costs prohibitive for some patients.



The information given to patients about where to go and how to get to their CT appointment is poor.

Specialist review



Specialist review can happen either in neurology or general medicine outpatients, or in AAU. Most patients go to AAU as they are seen the next day. At AAU, Kate will undergo further investigations.

Kate will be informed of her diagnosis, and will be referred to Capital and Coast DHB for neurosurgery.

There are cancer nurse coordinators assigned to patients who will accompany the patient through the journey. Kate may also be referred to a social worker/psychosocial report

! Telling the patient of the diagnosis is extremely important, as one patient put it: "The first time I heard the word 'cancer', I was scared." The patient may be on their own with no support, and may not take in anything that is said to them. The place where the patient is told may not be private.

! Referrals to psychosocial support can be late.



The cancer nurse coordinator and the Cancer Society are a great help to the patient.



Clinicians need to ensure the patient understands what is being told to them, and provide information on next steps.

In Capital & Coast DHB



Kate will be referred to neurosurgery at Capital and Coast DHB. Normally, patients will be at the AAU, so the referral is done a phone call, and the specialist in Wellington can see the images on the PACS.



If Kate is an inpatient, she will be transferred to Wellington as an inter-hospital transfer. If she is an outpatient, transport will be more difficult.

Kate will be admitted to CC DHB, and undergo surgery. From there, she will be transported back to Hawke's Bay hospital to stay as an inpatient.



The coordination between CC and HB DHB works well.



The histology report can be slow to come through.



Issues with family support and accommodation in Wellington. The National Travel Assistance Policy has restrictions.

In MidCentral and Hawke's Bay DHBs



**PN
HB**

While at Hawke's Bay hospital, Kate will await the results of the histology from her surgery in Capital and Coast. Once the results are in, there will be a regional MDM, which will decide the treatment plan and who the lead clinician in charge of her care will be (e.g. a radiation oncologist).

Kate may go home before her radiation therapy starts. At this stage, the patient may have done their own research on treatment options and if some options aren't offered to them in the treatment plan, they may question why.

Radiation therapy happens in Palmerston North. Kate will have her planning CT and FSA at MidCentral DHB, these will happen at the same time. For her treatment, she will stay at Ozanam House in Palmerston North. There is a shuttle available from Hawke's Bay to Palmerston North three days a week.

If Kate is having chemotherapy at the same time, this will also happen in Palmerston North. If chemotherapy is separate, this will likely happen in villa 6 at Hawke's Bay Hospital.



Ozanam House is excellent, as is the transport to and from there. Whānau are able to accompany the patient.

Waiting for test results is a very trying time for patients. As one patient stated: "The waiting is so hard."

Due to lack of integration of test results, notes etc between some health professionals, sometimes patient queries aren't able to be answered on the spot. The patient has to get their question answered at another time by a different clinician.

While in Palmerston North, if the patient's family hasn't accompanied them, the patient will not have any support, except for other patients. There are also no support people at Ozanam House. The patient may feel isolated, as they are away from home.

There may be poor communication and coordination of care between surgery, chemotherapy and radiation therapy.

There has been a large increase in the number of oncology patients, and Villa 6 is not fit for purpose.

At home



Following treatment, Kate will attend follow-up clinics in Hawke's Bay. She will also see her GP.

At some point in the journey, she may receive a palliative care referral.

There may be a lack of support services for whānau. As one patient stated: "We are the patient, but your family take a knock as well."

There is a stigma around hospice and palliative care, which may stop patients accessing it.

There may be a lack of coordination between primary, secondary and tertiary care, and it is left to the patient to sort.

Note: There were patients who attended this journey and generously shared their own experiences. The quotes used here are direct quotes from those patients, who gave their consent to be quoted.

9.1 How to improve

System changes

Participants suggested a ‘one-stop shop’ for diagnostics and treatment, to limit the places a patient needs to travel to and to potentially limit wait times and the amount of clinician services involved.

An agreed plan of care that is electronic, accessible, shared, and owned by the patient. The plan should be developed with the patient and their family, be adaptable and contain next steps so patients know what to expect. There should be one point of contact for the patient to call if they have any questions.

Make clinical information available in one place for staff so any conversations with patients can include on the spot answers e.g. scans, results, notes, rather than saying to the patient that they have to ask another clinician.

If oncology staff are positive, that has a great effect on patients. Ensure that the oncology team is resilient, and provide a good working environment for them. Have team-building days to help build positivity.

Incremental changes

Staff need to have the capacity, and be empowered, to make changes. Make it easy for staff to suggest small changes, and create a flexible system to make those changes happen.

- Improve facilities for patients receiving news, make it private and appropriate.
- Engage psychosocial support early on in the journey.
- Education to GPs on improving the quality of referrals for high suspicion of cancer.
- Increased CNS resource.
- ECA/RIS integration – add an FCT icon.
- Identify the need for an interpreter at the start of the journey.
- List of relevant services/support/information available to patient (e.g. on website, through an app, through partnership with Cancer Society).

10. Journey H: Paediatric Asthma

Dad and Mum arrived home after a church meeting to find their 10 year old son, Iosefa, struggling to breathe. His Dad takes him to ED at 8pm. It is his 3rd visit to ED in 3 months. The first visit was for a skin condition, and the previous visit was for a respiratory condition.

The family (Dad, Mum and 4 children aged 10, 8, 3 and 1) arrived in New Zealand 3 years ago from Samoa. The family have been living temporarily with their uncle, his wife, their 3 children and their father who is 65 years old. They all live together in a 3 bedroom Housing NZ home.

Seasonal works means the family is on one income for most of the year. The father is employed in seasonal employment and works long hours in the orchards.

Key reflections



While the journey through ED and the ward is relatively smooth, the key to this journey is how to stop him presenting to the ED in the first place. By increasing access to primary care and improving patients' health literacy, the health sector may be able to stop a lot of presentations to ED.

Care throughout the journey needs to be culturally appropriate. Particular care needs to be taken when talking to the patient and whanau to ensure they understand what it all means.



At the ED

Iosefa will arrive at the ED with his father, and will be seen first by the receptionist. They will be given forms to fill in.

The nurse will triage the son, and from there they will transfer into ED where a nurse will do a full assessment.

The nurse will initiate treatment without having to wait for the doctor. He will be monitored until the ED house officer arrives to do a further assessment.

Questions regarding smoking status of the family, and family violence will be asked.

- Observations performed by the nurse may be poorly explained due to time constraints.

- The staff may make assumptions that a nod from the father means he understands what is happening.

- In the waiting room, there is a lack of privacy. There may be other patients in ED (e.g. drunk or bleeding) that a child would find frightening.

- The need for an interpreter may not be identified at the right time in the journey.

- There may be a wait for the family after triage before transfer into ED.

- Social workers are only available in office hours.

- The receptionist may ask about eligibility/residency. This can go poorly if not delivered in the right way.



If discharged straight home from ED

The ED doctor will decide not to admit and will prepare for discharge.

The family will be provided an asthma action plan and a referral will be made to the Pacific Island Navigator/Nurse.

He will be discharged from ED and his father will be told to take him to the GP for a followup.



If admitted onto the paediatric ward

If the ED doctor decides that he needs to be admitted, the paediatric registrar will be called, who will come and see the patient.

Once seen by the registrar who agreed to admit him, there will be a nurse-to-nurse handover on the paediatric ward.

On arrival at the paediatric ward, the staff will discuss with the family about what happens next. In the morning, there will be a tour of the ward. A ward round will happen, and the patient will be assessed.

A family meeting will happen, where referrals will be made to services such as Breathe HB, Respiratory Nurse Champion, Healthy Housing. Staff will engage with the family about their GP status.

The family will get a discharge plan, which will be discussed with the family. They will go home with medications and spacers, as well as a script for more.



The family is able to take any spacers and inhalers they used home from ED, and the nurse will show them how to use them.



They will be provided with a discharge plan, however they may not understand the plan.



While they will be told to go to their GP, the family may not have one.



There can be a long wait for the family prior to discharge.



The nurse handover, which happens in the morning, happens at the bedside, to build relationships and the parents can contribute to the discussion.



There is a play room on the ward.



There is opportunistic immunisation on the ward, and a paediatric social worker during office hours.



There can be a wait for the paediatric registrar. By the time they are seen, the family would have told their story multiple times.



On arrival at the paediatric ward, parents are able to stay, but the sleeping facilities are not great.



During the ward round, the teams of doctors can be daunting for the family, and the doctors may not introduce themselves.

At home



The Clinical Nurse Specialist (CNS) will get the discharge summary and email the Respiratory Nurse Champion to followup with the family.

The Respiratory Nurse Champion will phone the family. If they cannot get hold of them, they will re-contact the CNS.

Pacific Island navigators will be working with the whole family, education and making referrals where needed. They may make referrals (if these haven't already occurred) to Breathe HB, Child Healthy Housing Team, Whanau Wellness, PHN at school.



The family may not go to the GP after discharge. They may not have one, or there may be other barriers to attending, despite the appointment being free for the patient.



Pacific Island Navigators can help the family with the whole journey – but not all families are referred to one.



There is a good range of culturally responsive support services in the community.

10.1 How to improve

System changes

The language the health sector uses is important – rather than saying families don't engage with primary care, frame this in another way e.g. the family is 'underserved by primary care'. The former sounds like we are placing the blame on the family. The health sector needs to empower patients to take control of their health care.

The health sector needs to shift the focus from managing the symptoms to focussing on the wider story – looking at the social determinants of health (e.g. housing), and looking at the wider family's health. The family need to be involved in the planning and education. Increasing workforce diversity would also help.

Incremental changes

- Create an electronic prompt for pacific health referral at the hospital, so all patients are referred to the service.
- Train staff in cultural competency.
- Have resources available in all Pacific Island languages.
- Community education about what ED is for.
- Pasifika support at ED, and more Pacific Island navigators available in both primary and secondary care.
- 24/7 access to social work in the hospital.
- Practice Nurse delivered asthma education.
- Electronic prompt for pacific health referral, to ensure all families get referred to the service.
- Identify the need for interpreters early, and bring them in as close to the start of the journey as possible.
- During waiting times, have simple games available for children to help them learn about asthma.

11. Journey I: Diabetes and Kidney Disease

Rangi is a 50 year old Maori man who lives in Wairoa.

He has a history of uncontrolled diabetes and presents to Wairoa ED with symptoms of end-stage kidney disease.

Key reflections



A key reflection of this journey is the access to health services if a patient lives in a remote area. Living in Wairoa meant there was more travel involved to get required care, including allied health and dialysis.

Participants noted that increased contact with health professionals, and seamless interaction between health professionals, would help improve the patient's health literacy and provide him with tools to better manage his condition, keeping him out of the hospital for as long as possible.

At the ED



Rangi will self-present to Wairoa ED, where he will be seen by a nurse when he arrives. He will be seated while awaiting action. The nurse will then triage him.

The nurse will do observations and tests and phone the GP on-call, do a handover and await orders.

The GP will arrive within 30 minutes, where a decision will be made to transfer him to Hawke's Bay Hospital.

At Wairoa ED, there is only one RN available after hours, who will cover multiple roles e.g. reception, security. The RN may be juggling multiple patients.

There is limited food available for patients.

The nurse will keep Rangi well informed of what is going on.

It can be difficult to arrange transport to Hawke's Bay Hospital. It can take many phone calls, and is weather dependent.

At Hawke's Bay Hospital and transfer home



Once transferred to Hawke's Bay Hospital, Rangi will go to ED where he will get more tests. It will be hours before he goes to ward A1. He will be far from home and will want to return.

On discharge, a discharge summary will be sent to Rangi's GP within 24 hours.


Rangi will travel by bus back to Wairoa, where the bus will drop him in the hospital carpark.

As Rangi wants to go home, he may say he is feeling OK, when he actually isn't.

He may be sick on the bus ride home, and other patients have to assist him. If he is feeling very sick, he may end up back in Wairoa ED. Once at the hospital carpark, the patient still needs to get home, but there is limited/no public transport or taxis.

There is varying quality of discharge planning, and discharge summaries can have medication errors. Wairoa Hospital isn't involved in discharge planning and will not be notified.

At home



Rangi would have been informed that he needs to make an appointment with his GP as a followup. He will fill his prescriptions also during working hours.

There is a renal team that visits Wairoa monthly, so Rangi will get a specialist review. The appointment would be generated while he was at Hawke’s Bay Hospital. The specialist will set up recalls. Rangi will be referred to the diabetes CNS, social worker, Healthy Home, and Smokefree services.

All referrals get sent to the GP, who will stick to specialist recommendations for treatment. Rangi will need dialysis, which can happen at home, provided the patient’s home situation is suitable (e.g. has a constant water supply). If it can’t happen at home, he will need to leave Wairoa. There is private transport provided to Hastings on Monday, then the patient travels back on Friday where he is taken home.

District Nurses are available to provide some palliative care.

Thumbs up: All GP practices are VLCA in Wairoa. There is intensive followup of the patient by GPs, once they are discovered. Dialysis support is intensive in the community.

Thumbs down: Rangi may not have a GP. He may also not be able to afford to fill his prescription. The pharmacy in Wairoa is not open after hours. Dieticians only visit every 2 months, and do not do home visits. There are no physio, OT or rehab services available in Wairoa.

Thumbs down: Communications between GP and specialists are not always visible, and specialist services are not connected. District Nurses are not available 7/7, and there is no hospice facility in Wairoa.

11.1 How to improve

Participants identified a wide variety of improvements to the current system:

- Increased education of options for people with renal failure.
- More support guidelines for communication between GP and specialists.
- Discharge facilitator in Wairoa.
- Wairoa-specific MDT.
- Complex discharge nurse role – who will support discharge and follow-up.
- Dispense from DHB three or four days’ worth of medication as may be a delay until patient can get prescription filled.
- Whānau screening.
- Mobile PN clinics.

12. Journey J: Ear Disease

Hamiora, a 4 year old Maori boy living in Wairoa, fails the hearing screening at the B4SC. He has a history of recurrent glue ear.

Key reflections



The screening of hearing issues seems to work very well with a number of points of checking and re-checking. The service response has been worked through and the otolaryngologist and audiologist both run regular clinics in Wairoa but there is a sense that not all demand can be met through existing resources. The high DNA rate for the outpatient clinic is a real issue (around 25% do not attend).

Attendance rate for surgery in Hastings is high. The service is, however, over-subscribed and the level of declines is significant. Primary care indicates that older age groups are turned away from the service and primary care indicates is simply refers back in as there is nothing more it can do. There is sense the community is used to putting up with ear disease.

The diagnosis



Screening takes place at Early Childhood Centres or Te Kohangarao by the Tamariki Ora provider. If not enrolled in early childhood care then screening will take place with B4 school checks.

The audio-technician comes up to Wairoa 4 times a year to undertake the testing.

If the child fails the VHT test then they will be given another a retest after 3 months. If they fail again then they will be referred into the ENT service. The GP is notified of this referral.



There are several checkpoints to ensure a child has been screened. The first check is with the Tamariki Ora provider. If not, then with the GP and the nurse will enrol the patient. If not then, then at school. Compliance is high at 95%.



There is considerable effort in tracking down children. The dental record system and the immunisation register are used as a cross reference point.



There is a safety net for transient children and the DHB is alerted, or alerts other DHBs, when children move.



There is considerable acceptance of ear disease and the consequence is we tend to pick it up late. NZ has a very high rate of chronic ear disease and is ranked 5 highest in the world. th







At outpatient clinic



A tympanogram will be administered and the child will be referred to:

- An ENT specialist if the test is negative and an ENT specialist will triage the patient and prioritise the referral.
- An audiologist if the test is positive.

There is a once a month ENT clinic in Wairoa for ENT and audiologists, but the booking is done in Hastings.

-  The booking tries to fit the visit in with the patient's other activities.
-  Under 8 year olds are prioritised. However, beyond that, there is little agreement about who else and how to prioritise.
-  There is an issue with follow-up of children with resolved hearing loss. They are not easy to identify.
-  The DNA rate is very high because the service is dealing with people with complicated lives.
-  The ENT service is under considerable pressure and another ENT specialist is being recruited.
-  If there are three DNAs then the person will be ignored.

If surgery is needed









Patients are reviewed as a group and bookings for surgery made. At this point, there is full agreement on priority. The booking for surgery will be made from the Wairoa clinic.

Pre-operative clinics are organised so it can all be done on the one day.

Surgery is performed in Hastings.


Paracetamol is given for pain relief afterwards.

-  Non-attendance is very low after the first clinic.
-  The "dry tap" rate is very low and possibly too low.
-  The booking clerks have a stamp indicating the patient is from Wairoa.
-  Wairoa patients stay in a whanau house and need to be overnight.
-  There is very poor patient information about what to do after surgery or the effects of having ear interventions. Patient information is given out but usually not read. Thus patients may feel, for example, they can't swim.
-  Theatre capacity is a huge problem.



Follow-up

There is a hearing test at 6 weeks, performed by the specialist service.

-  This follow-up could be done by someone other than the specialist, to free up specialist time.

12.1 How to improve

There are a number of areas to improve on:

- Increase the profile of ear disease so more people are on the look-out for it.
- More health literacy is needed about chronic ear disease both generally and specifically with patients.
- The specialist service needs coordinated support for appointments. There is a possible local solution to increase the DNA rate whereby the dental service and others will notify the school to make sure the children are reminded to come to the session. Appointment times could be shared with family support.

- One person is needed to coordinate DNA follow-up and the fact of the DNA needs to be shared locally and with the GP.
- Follow-up of children post-grommets later in life would be useful. However, follow-up post-surgery could likely be done by others outside the service.
- There could be testing of children before the age of four.
- There could be a wrap-around service for whānau as glue ear might indicate others with glue ear or other issues.
- Access to audiologists is difficult and there could be more primary care access to audiologists.
- Implement a one-stop shop in high risk areas.
- Patient education could happen on tablets in waiting rooms.
- The service needs mobile access to patient records.
- Research chronic ear patients and clinic attendance correlation.

13. Journey K: Dementia

Scenario A:

Gracie is an elderly woman with mild dementia living in rest home level care in Central Hawke's Bay. She develops a UTI, and comes to the attention of the rest home care worker at 11pm.

Scenario B:

Gracie is an 82 year old woman living at home alone in Central Hawke's Bay. She has mild dementia, and is seen by a caregiver 3 times a week. She lives in town and her daughter also lives here.

Key reflections



For want of some input from a GP, the journey becomes a very long one, and the frail nature of Gracie is not dealt with well in hospital. The consequence is a long time in hospitals and possibly a reduction in Gracie's functioning, which may not be recovered.

For the journey from Gracie's home, this journey shows the importance of access to the general practice team. Standing orders for nurses to give antibiotics and a follow-up with the GP would be a clear and obvious step. After hours, nurses are the only ones who hold the meds, as the pharmacy is shut. There is after hours pharmacy and dispensing but this isn't well known.

For the journey in the rest home, there was some debate on GP availability during the day and after hours, and some difference of opinion between the practice and the rest home as to whether the patient would be seen.

Other reflections:

- Acuity in care in rest homes has increased but staffing hasn't.
- The key issue was getting the prescription and the antibiotic to Gracie.

Scenario A: Issue identified at the rest home



The Senior Healthcare Assistant would notice pain and discoloration in Gracie's urine at 11pm.

A standing protocol is triggered:

- The Registered Nurse would be called at 11.05pm. The Registered Nurse decides whether to go or wait, and then call again later. If away, an RN in Hastings would be giving telephone advice.
- 15 minute checks instigated
- A sensor mat is likely placed in the room.

The RN instructs increased fluids and prescribe paracetamol (but can't prescribe antibiotics). In this example, the Registered Nurse is on-site by 11.15pm and would administer charted medications.

Ambulance is called.

Family is notified after the ambulance is called around 11.30pm.

Transport

The ambulance responds with a call from the call centre to see whether interventions have made a difference.

The ambulance arrives in 30 minutes to 1 hour. Most ambulance transfers take 2 to 3 hours.

Transfer would be straight into ED through the ambulance transfer entrance.



There are clear protocols in place. The rest home nurse would be called and could authorize administration of some medicines but not antibiotics.



The RN has already done a day's work and will have to work tomorrow as well.



Could also be that the challenging behaviour has become more challenging and Gracie might need 1 to 1 attention which would not happen.



The focus on Gracie means the other Health Care Assistant is managing 32 other residents.




15 minute checks are difficult to achieve.



GPs are on-call after hours but the rest home doesn't feel like they have access or support from the GPs.

- ! With mild dementia, some antipsychotic drugs may be prescribed, which may increase the incidence of falls.
- ! Might be one hour to two hours and then the RN would think she may not be able to manage. At this point the ambulance would be called.
- ! All residents have an advanced care plan. They likely will have an enduring power of attorney but that would not be invoked. EPOA instructions from family can conflict with advanced care plan notices.
- ! The family would not be called while the RN is trying to de-escalate, partly as, if there is delirium or other issues, family may not help the situation.
- ! Rest home staff have change in behaviour, de-escalation training. The RN supports the staff in dealing with this situation.
- ! ED can be called for advice but do not like giving telephone advice. They will likely say bring them in.
- ! Hopefully there would be a patient plan in place but the GP is sometimes calling in at 8pm to make these plans and the RN may not be there. Now the RN is called and comes in too.

At the ED



Gracie will be triaged. Gracie would be triaged at 3 unless sepsis which would be 2.

ED will call the medical register.

Gracie will be given antibiotics and a drip. Medical registrar will assess Gracie and talk to the coordinating nurse.

In ED, they would do hourly observations.


A bed request will be entered in the system and goes to the duty manager. It may take an hour for bed allocation.

An orderly is called and Gracie is transferred at 8am.

ED nurse would fax a form through with EWS to the ward nurse.

- ! Whatever happens in ED happens slowly. The patient would be distressed and, delirious. Have deliria in addition to dementia.
- ! The Medical Officer could have 9 to 10 patients backed up – each of which will take a 30 minute assessment time.
- ! Gracie could be in ED until 6am.
- ! She is likely suspicious, non-compliant, there are no familiar faces. She will know there is something wrong. Likely stressed but not distressed.
- ! In terms of how she is feeling – she is possibly 9 to 10 out of 10 (10 high) in terms of anxiety. Initially she would have been 2 to 3 in the rest home escalating to 7 to 8 in the ambulance.
- ! If given morphine in the ambulance, may diffuse the pain, but then would end up in ED with bright lights and lots of activity.
- ! There might be some tension in the hand over. In our process we leave an hour for the bed. An orderly generally turns up in 15 minutes although patient reported 45 minute wait. If unlucky not until 8am.

If Gracie goes to AAU



Gracie will likely go to AAU and the aim would be to turn her around in 24 hours. Orderly transfers Gracie to AAU.


Older person's mental health is called for assessment in the morning.

Gracie will be rehydrated, and depending on her state, may be tied to the bed.

The charge nurse from AAU calls Orbit at 10.30am. Seen by Orbit team at 3pm.

A falls assessment would be done

If Gracie goes to the medical ward



Orderly transfers Gracie to medical ward. Gracie would stay overnight.

Medical discharge at 8.30am on day 2.

NASC is called and there is input from the physiotherapist and geriatrician while on the ward.

The pathway from here is less clear. In this case, Gracie will be transferred as a 2-week medical patient in Central Hawke's Bay, in hospital-level care.

- May have been catheterised and likely would pull it out.
- Likely she would have urinary retention. No call bell within reach. Would need to get up to go to the toilet. Common to be incontinent.
- Likely to have confusion issues and likely also to have less ability to express herself. Could try to climb over the bed rails.
- Delirium and dementia have ramped up. Will be deconditioned. Would have been awake all night. Would sleep all day and have deteriorated as not moving.
- She would not be functionally good enough to return to rest home care.
- At that point, someone will notice she is from Waipukurau.
- Gracie may be medically ready for discharge at 8.30 am on day 2 but needs 2 nurses to mobilise, who may not be available.
- NASC may list Gracie as hospital-level care without the opportunity for rehabilitation.
- The sign off from the geriatrician can be a problem.
- It could be a referral to the older persons mental health team, but there may be a standoff as that is not their job.
- The GPs won't do a capacity assessment in CHB.
- The GP has to accept Gracie for her to be returned to CHB.

Scenario B: Issue identified at home



Caregiver arrives, notices a problem with Gracie and contacts agency co-ordinator. The co-ordinator contacts next of kin or RN. In this case, the daughter.

Caregiver leaves. Daughter calls GP from work.

In General Practice

Receptionist gets a call from the daughter. The receptionist would refer the call to a nurse, who would ask that Gracie come in.

If the daughter was unable to transport Gracie to the GP, the GP could phone the Red Cross to take Gracie to the GP. More likely the GP tells the daughter to call an ambulance.

In this instance, Gracie gets to the doctor and is given a script and sent home. Daughter drives Gracie home.

The Nurse Practitioner might contact NASC for an improved package of care.

The next day

In this care, there is no improvement in Gracie's symptoms, and she is left overnight. The caregiver finds her in the morning on the floor.

Caregiver rings agency and rings ambulance. Gracie is taken to ED.

- Gracie is scared and stressed which stresses those around her. As people become more confused, they feel embarrassed, defensive.
- Daughter at work and will become anxious.
- May not be able to get in to the GP the same day, GP may have no available appointments.
- The daughter needs to leave whatever she is doing to bring her in. She may not be able to leave work.
- The practice may not be aware Red Cross is available to bring Gracie in.
- No 24 hour packages. Reality is NASC doesn't have the level of service she needs. Max 3 hours a day. But the GP can admit her to a short term rest home bed. More typical to send Gracie home.
- Caregiver who found the problems would have left already. Their supervisor wouldn't call the GP. It is up to the daughter to ring the GP.
- Receptionist gets call – the response depends on how the information is relayed. If it doesn't sound urgent then the receptionist will offer an appointment later that if felt urgent. The daughter would need good health literacy to be able to relay the appropriate information.
- Often when calling the GP, there was only one answer – ring the ambulance.
- There is "the book" at Gracie's home with names of contacts, caregivers, doctors.
- Picking up a prescription is a real barrier. CHB does deliver medicines.

In this case, there is no improvement in Gracie's symptoms, and she is left overnight. The caregiver finds her in the morning on the floor.

Caregiver rings agency and rings ambulance. Gracie is taken to ED.

(Gracie is now in ED and the journey is the same as for Scenario A from here)

At the ED



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ED will call the medical register.

Gracie will be given antibiotics and a drip. Medical registrar will assess Gracie and talk to the coordinating nurse.

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Gracie may be medically ready for discharge at 8.30 am on day 2 but needs 2 nurses to mobilise, who may not be available.

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The sign off from the geriatrician can be a problem.

It could be a referral to the older persons mental health team, but there may be a standoff as that is not their job.

The GPs won't do a capacity assessment in CHB.

The GP has to accept Gracie for her to be returned to CHB.



Possible shift to rest home

If Gracie was unable to return home, or if the need was identified for palliative care, the hospital would talk to family and contact GP.

A range of issues were raised as to rest home access – there may be a five year wait.

There needs to be a supervising GP if it is determined that Gracie needs to be moved to a rest home.

Only choice for someone not dying at home is a rest home.

13.1 How to improve

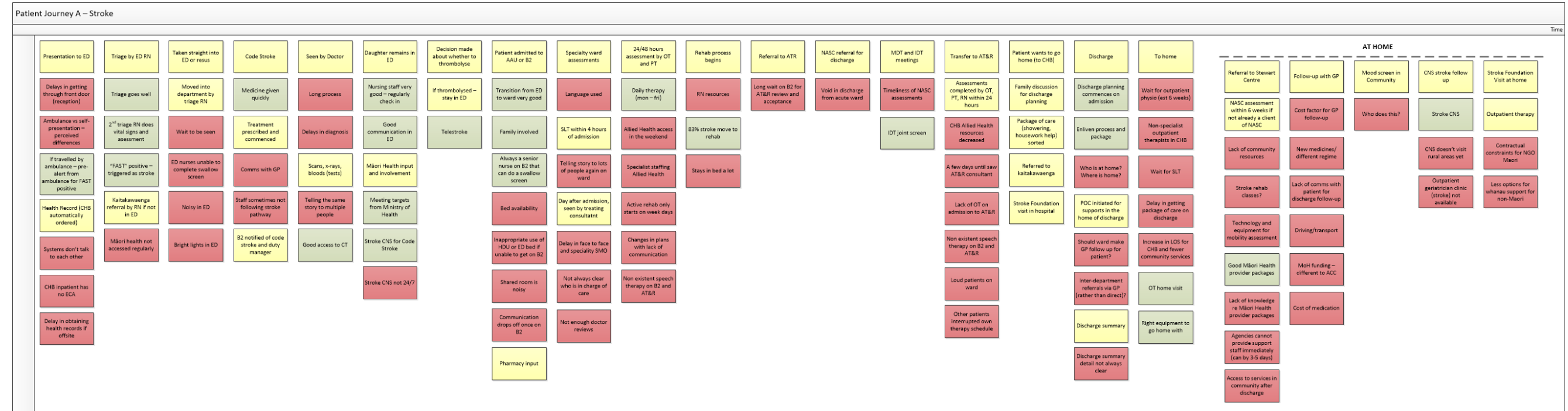
Some suggestions were:

- Emphasise the need for respect of the elderly, together with the need for an advocate much like a Children's Commissioner.
- There could be a process plan for UTIs, and could also bundle in with resuscitation activities. As part of this, there could be standing orders.
- Possibly, a facility GP – but likely would only be available for, for instance, a Wednesday afternoon.
- Remote medical support to the rest home would work in this situation.
- The rest-homes need some way to flex-up staffing when acute situations present.
- An aged care person could come and work with GPs and that could be a nurse practitioner.
- There is no physio support in the rest home other than that designed for maintenance meaning rehabilitation is unlikely.

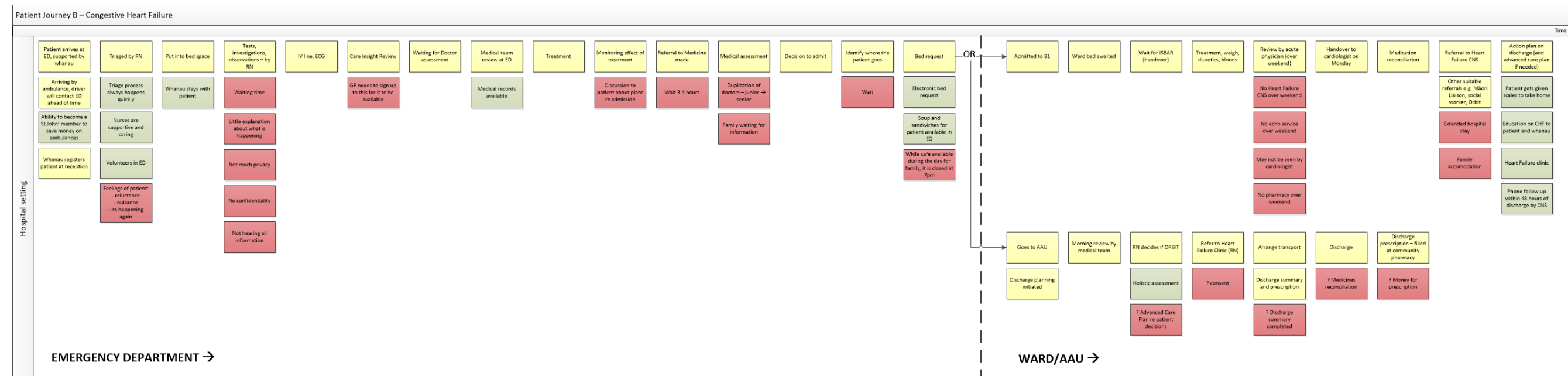
- Identify patient risk factors earlier particularly if there were a history of UTIs.
- Admit directly to acute care for the elderly ward.
- Fast track through AAU as she is not that sick.
- Provide an urgent care response direct to the rest home possibly using the paramedics.
Or introduce IV management in ARC and with District Nurses.
- Introduce mattresses designed to avoid pressure injury.
- A dementia friendly ward.
- Telemedicine may assist with remote clinical support.
- Full implementation of MediMap meaning doctors can chart remotely.

Appendix 1 Diagrams of each journey

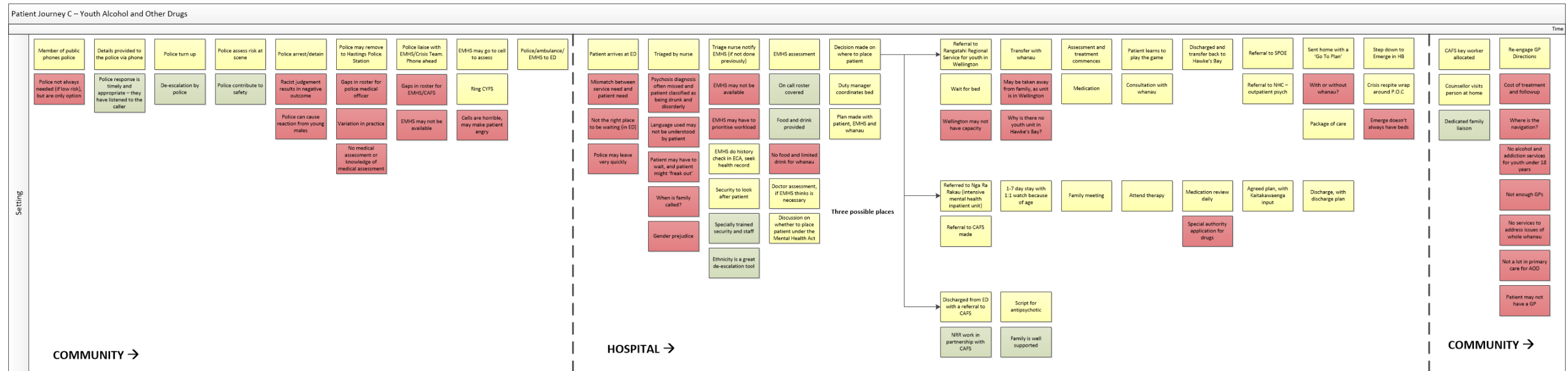
Stroke



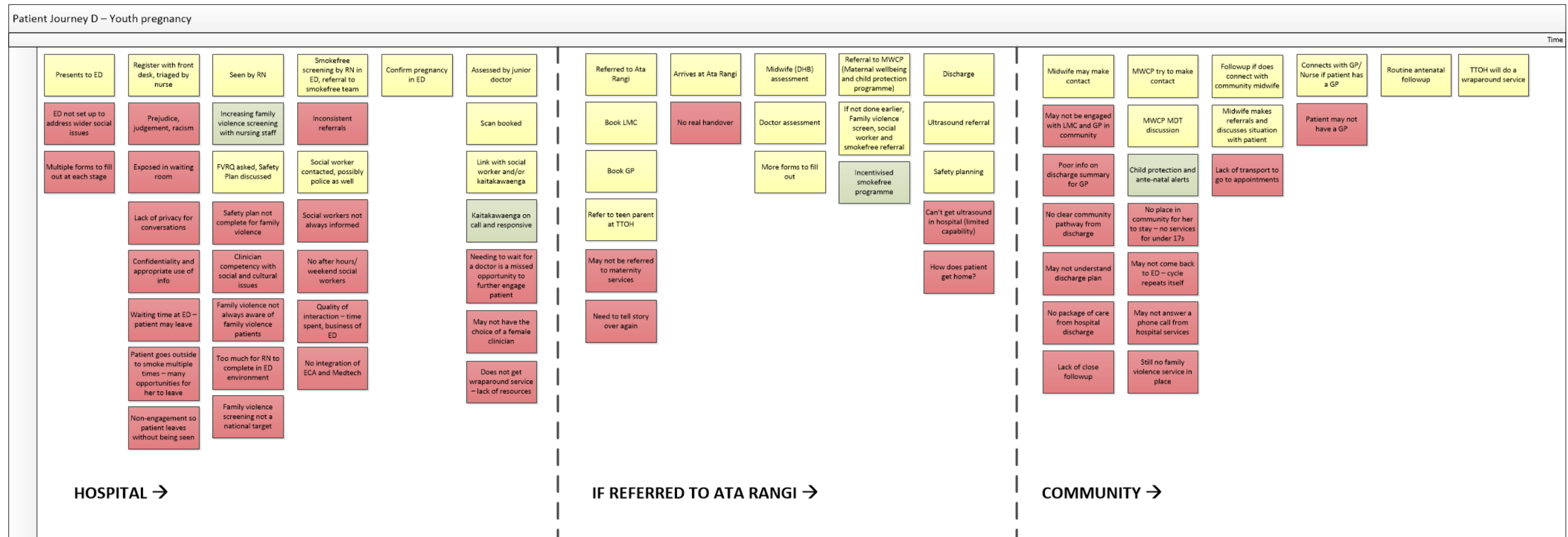
Congestive Heart Failure



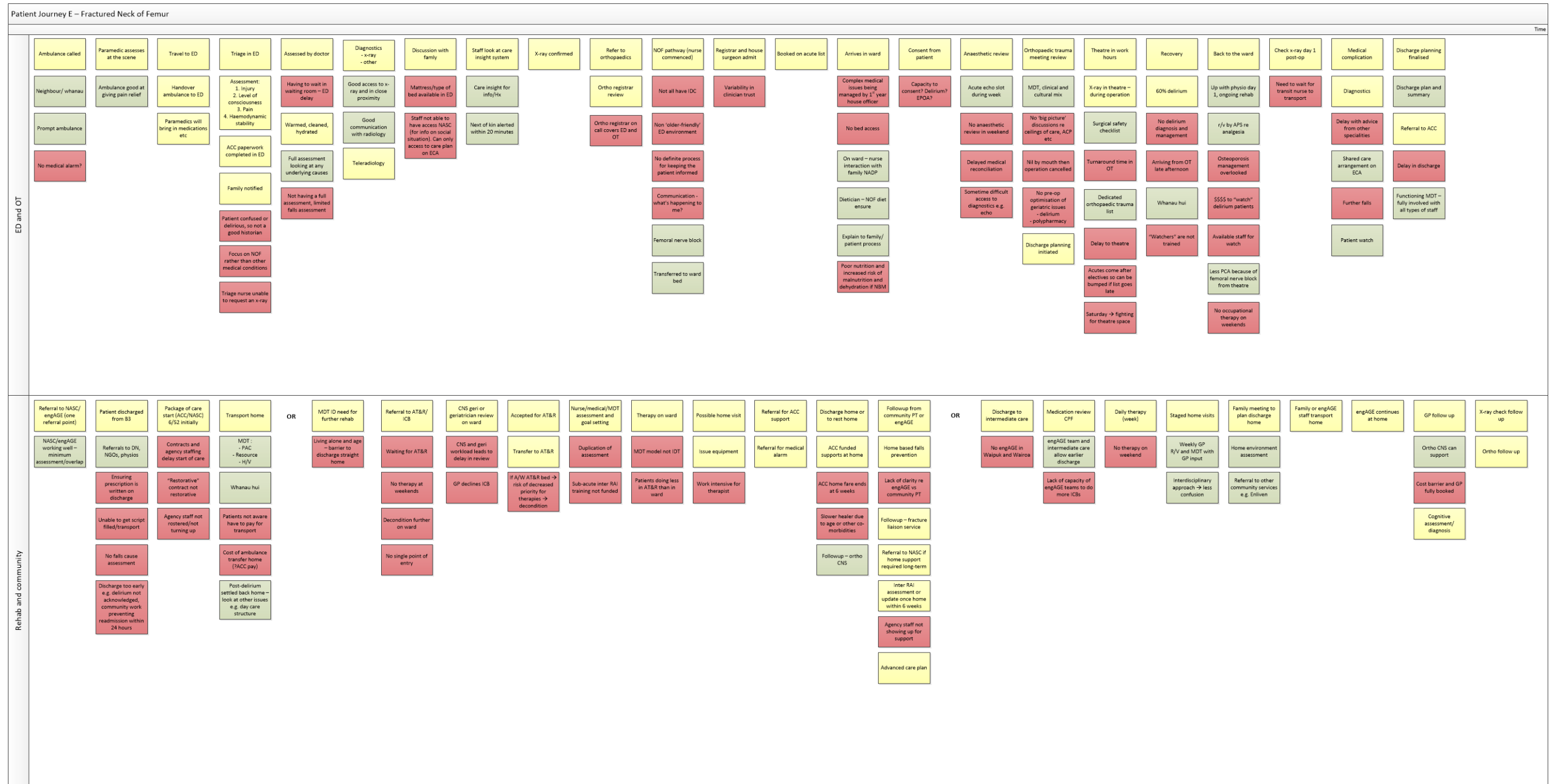
Youth Alcohol and other Drugs



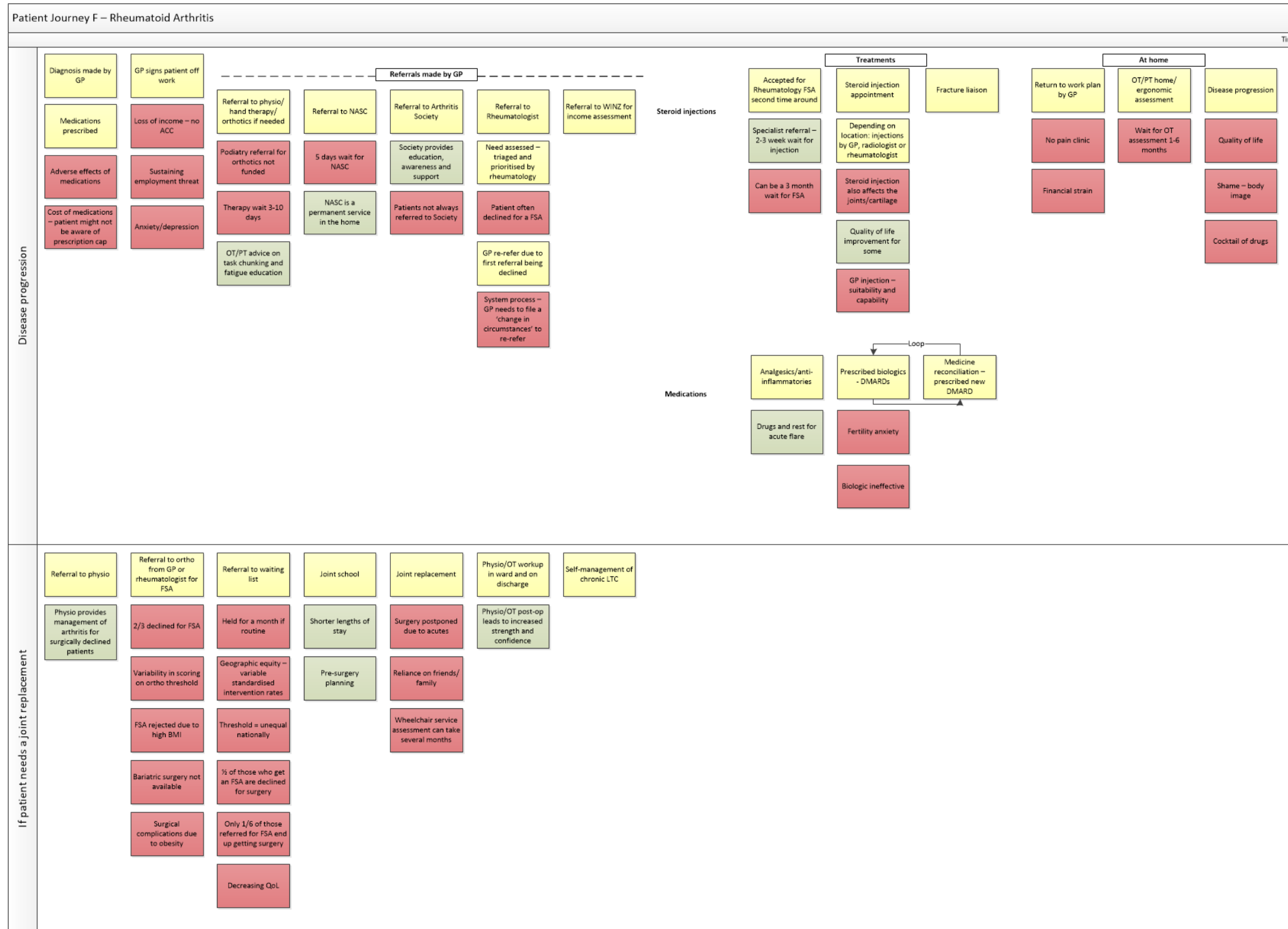
Youth Pregnancy



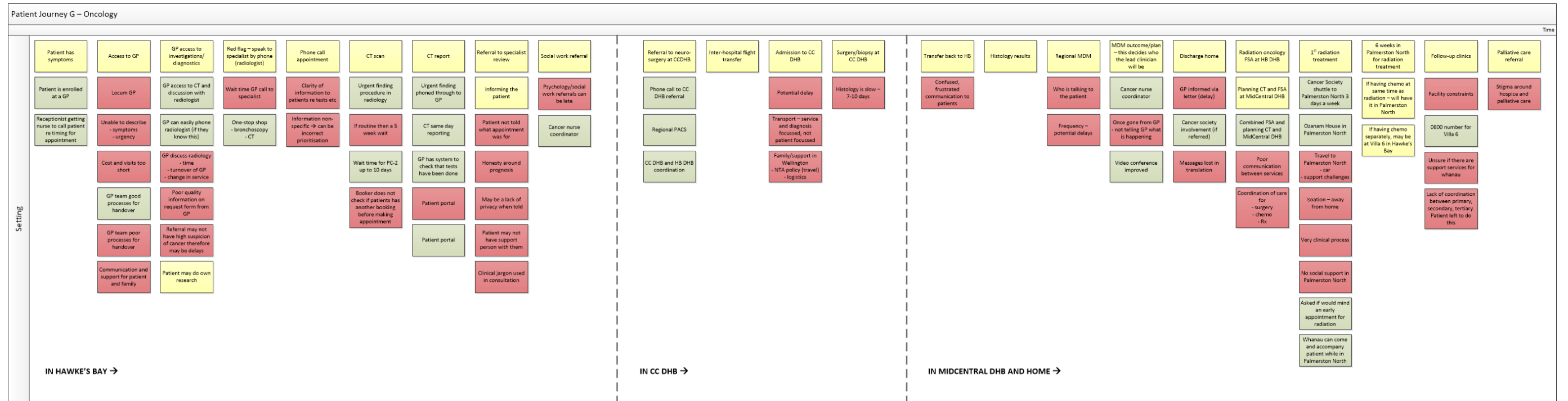
Fractured Neck of Femur



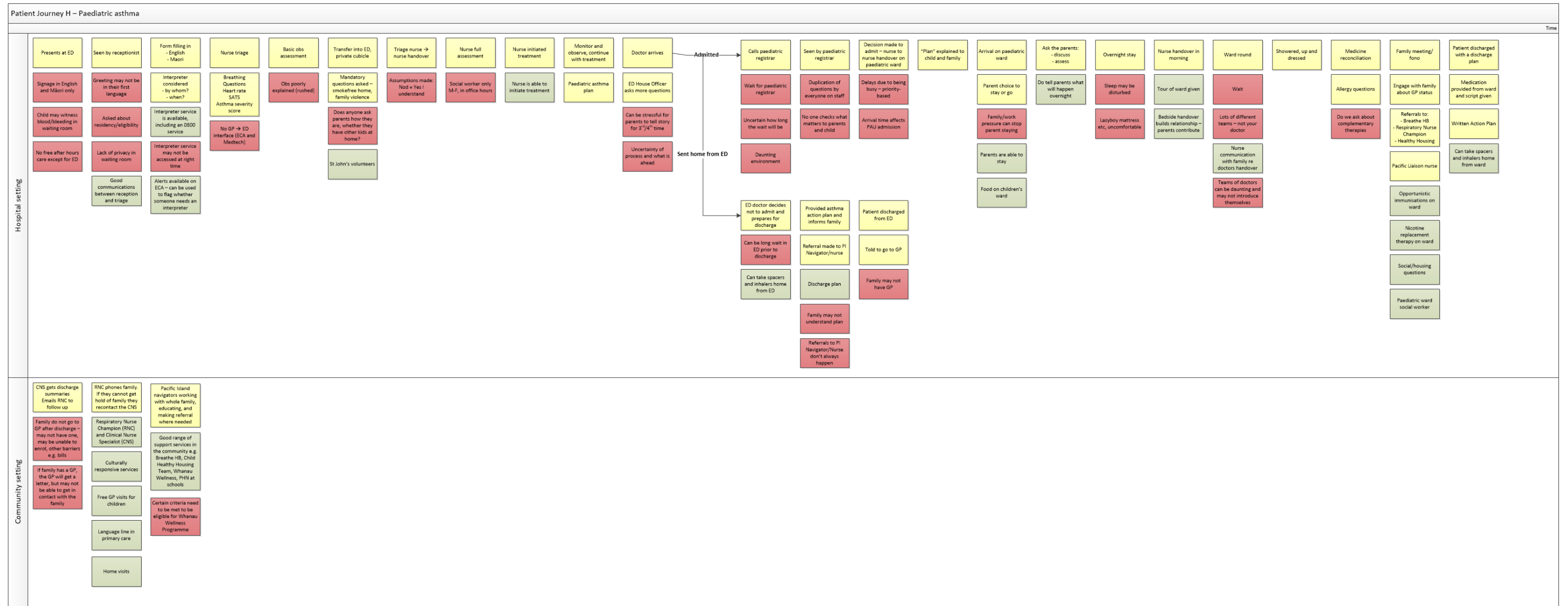
Inflammatory Arthritis



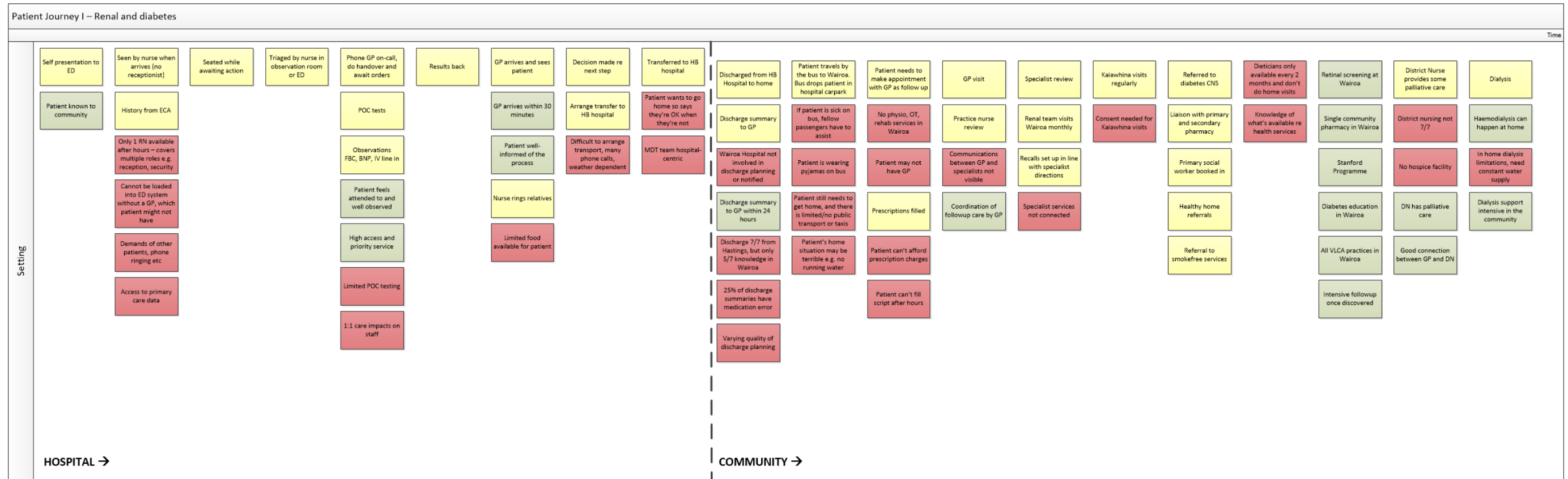
Tertiary Oncology



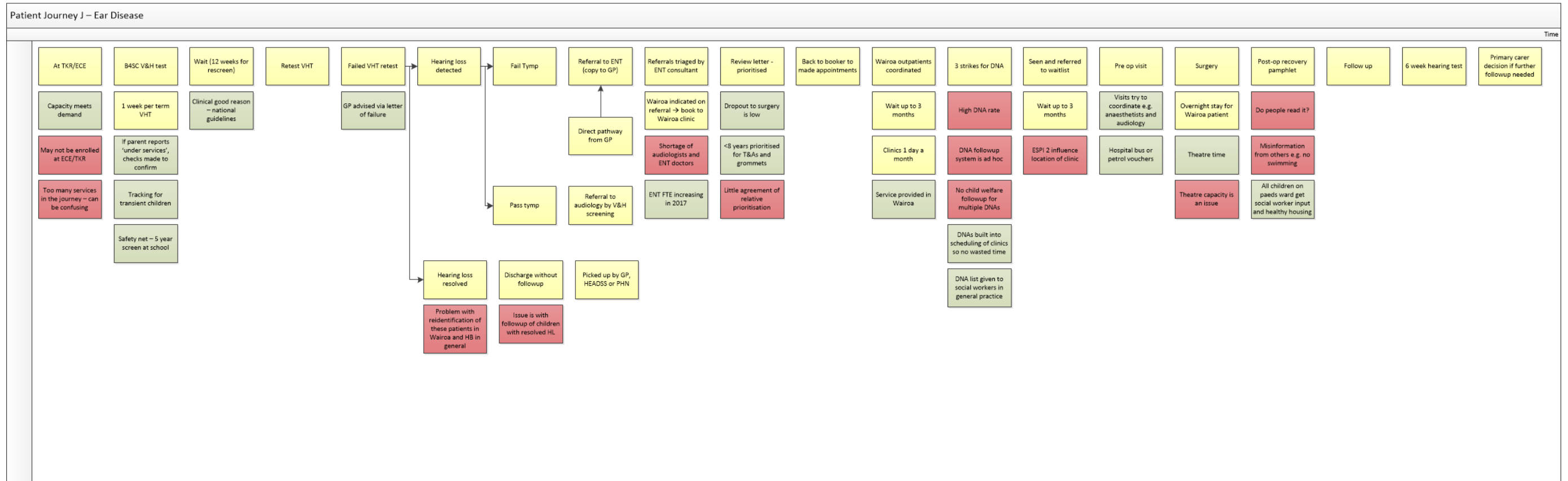
Paediatric Asthma



Diabetes and Kidney Disease



Ear Disease



Dementia

