# P1. PREVENT MEDICINES HARMS

Focus: Prevent harms from disease – drug – disease/drug interactions.

# Insights from development phase:

### **Medication reviews:**

- Many patients on multiple medications without review, increasing the risk of unnecessary prescriptions and adverse effects.
- Anti-psychotics leading to metabolic adverse events (weight gain, diabetes, hypertension etc). Particularly off-label use where there is no monitoring.

## Challenges for patients managing multiple medications:

- Anxiety in daily planning in relation to taking multiple medications correctly.
- · Forgetting to take medication.
- Some focus on a 'primary' medication or condition, prioritising it while neglecting the others.

## Varied understanding and attitudes towards medication:

- · Confusion around medications and what they are for.
- Skepticism and reluctance around taking medication.

## Access and availability challenges:

- Issues accessing prescriptions having to visit different locations, timings of ordering them, communications with prescriber and pharmacy.
- Some resort to taking medications not prescribed to them, often from family or friends, due to perceived need or difficulty accessing themself.

"we are very reliant on medication, we have to put a lot of trust in the prescription"

"even if I don't take the rest, I make sure I take that one"

"I don't want to get into that cycle where you need more and more medication to control the same pain"



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# P2. PREVENTING LOSS OF HEALTHY LIFE

Focus: Prevent deterioration or accumulation of physical and mental MLTCs leading to reduced quality of life.

# Insights from development phase:

### **Social determinants**

- Housing, amenities, environment affecting health/accelerating MLTC (air quality, housing, access to green space).
- Working conditions, unemployment and job insecurity affecting health/accelerating MLTC.
- Community & voluntary org. are often vital for supporting well-being and preventing health deterioration (especially in underserved areas).

## **System inefficiencies**

- Mental health decline while on long waiting lists.
- Patients can feel passed between services without receiving answers or effective treatment, which can lead to frustration, disengagement, and deteriorating health.
- Lack of primary and secondary prevention; leaving conditions to advance and become complex.

## **Health professional cultures**

 Negative experiences during diagnostic processes for 'contested conditions' (e.g. long-covid, ME, fibromyalgia, pain, fatigue) leading to delays in diagnosis, feelings of invalidation, and worsening symptoms.

## Individual-level factors

- Some people are unlikely to engage with health system until they are seriously unwell because of previous negative experiences, trauma, distrust of health system, access issues, cultural issues etc.
- Behavioural, lifestyle and attitudinal factors.

"I just kept going back to the doctors and it stretched over a period of years... getting nowhere... and it got to a point where I thought I can't manage. I was in a really dark place."



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# P3. LIVING WITH COMBINED PHYSICAL AND MENTAL HEALTH CONDITIONS

Focus: Better supporting people with the burden of living with MLTC to improve self management.

# Insights from development phase:

# **MLTC-induced challenges:**

- Managing the unpredictability of life with MTLC hard to plan ahead, unpredictable interactions between symptoms/illnesses.
- Overwhelming burdens of information, navigation, administration, prescription & polypharmacy.
- Social exclusion, stigma and psychosocial impacts.

### Access to information & resources:

- Accessing trustworthy information: Spending lots of time on Google, online forums etc. looking for support "going down rabbit holes".
- Self-efficacy requires having access to one's own data in a way that can be understood.
- Digital exclusion and poverty particularly in older adults without commodity internet or internet– enabled devices.

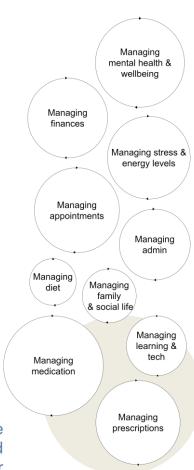
# **Contextual integration:**

- Social and economic context embedding and connecting services with wider housing, employment, childcare, amenities, environment, etc.
- Constellation of support required community & VCFSE plays a big role here.

# Behavioural, lifestyle & attitudinal challenges:

- Predisposition to managing "my most important illness".
- Acceptance of disability / potentially chronic and poor prognoses.

'Living with MLTC' section of journey map: people describe feeling overwhelmed "juggling" and managing all of these alongside living with their symptoms.



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# P4. DIGITALLY ASSISTED CASE MANAGEMENT

Focus: What would enable healthcare professionals to use technology to provide better care?

# Insights from development phase:

- Poor data relevance / utility for a given stakeholder.
- How and why data/information are produced, communicated and consumed in health and care system networks, emphasising a utility for action model for the information consumer (cf. EHR interoperability and simply copying clinical correspondence to patients/other healthcare providers).
- Rationalise data collection for a clear healthcaredelivery purpose.
- Lack of data driven insight for a holistic understanding of patients & their complex lives.
- Lack of facility to provide relational care "if technology doesn't free people up to provide care, then what is it for?"

- Lack of data sharing between services (resulting in repeated efforts, inefficiency, fragmented care).
- ChatGPT may not be the answer to everything.

"Only ask me to use technology if it improves patient care or makes it easier for me to provide patient care"

"We are not defining, storing, processing, presenting or sharing data in a way that is useful to any stakeholder".

Clinicians feels like they are "spinning plates" as well as patients



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# P5. COLLABORATIVE CARE NETWORKS

**Focus:** To manage a person's care across the siloed and fragmented primary, secondary, physical and mental healthcare system, requires assistance for that individual – a "personal assistant" for MLTC.

# Insights from development phase:

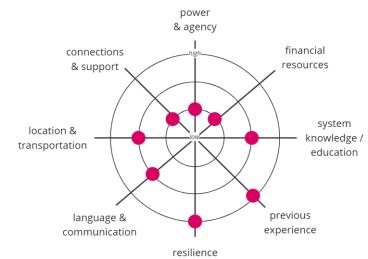
## Fragmented care:

- No continuity of care; fragmented and siloed care; need for relational care.
- Inefficiency in networks of communication between services as well as with patients.
- · Patients having to repeat story every time.

## **Access & navigation:**

- Navigating the health system on your own without support is impossible.
- Difficulties attending multiple single condition appointments people with complex lives particularly disadvantaged. How might we reorganise care systems to assist people to be more self-efficacious e.g. self-referral, flexible appointments / booking?
- · Low literacy & digitally excluded.

# Care and support needed for carers of people with MLTC.



Dimensions used to explore capacity for system navigation in person maps.

"What if you could get all your tests and answers in one place in one day not months and months?"

"In the mornings I don't feel like I get dressed anymore. I feel like I put armour on every day to protect myself from the battles I'm having to fight"



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