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MLTC Models of Care Team Science project

Progress, end of year 1

Jo Butterworth
December 2025

What is a Model of Care?

“a way of delivering health and care services that ensures the best possible outcomes for individuals and groups of people living with MLTC”

“define the principles, values, roles, and practices that guide how care and support are provided throughout the stages of MLTC”

Objectives for MLTC MoC Team Science

- Identify ‘top 10’ research questions that focus on patient priorities
- Priorities will be related to 3 structural elements for Models of Care (MoC) for MLTC:
  - Infrastructure & human capital elements
  - Organisational structure
  - Costing models
- This focus will ensure findings and recommendations translate to policy and practice

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Research prioritisation is to be guided by:

- Team expertise, networks (including NIHR infrastructure)
- Stakeholder engagement and embedded PPI
  - to ensure our work will benefit its recipients
- Existing evidence (scoping review)
- A systematic Priority-Setting Partnership (PSP) … year 2

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Cross-NIHR-Collaboration for MLTC - **Models of Care Workstream**

Co-Leads
Andrew Clegg, University of Leeds, **Geriatrician**
Rachel Johnson, University of Bristol, **GP**
Members
Kamaldeep Bhui, University of Oxford, Epidemiologist, **Psychiatrist**
Pete Bower, University of Manchester, **Health services researcher**
Jo Butterworth, University of Exeter, **GP**
Steve Callaghan, **Patient and Public Representative**
Felicity Dewhurst, Newcastle University, **Palliative Medicine**
Hilary Garrett, **Patient and Public Representative**
Vicki Goodwin, University of Exeter, **Physiotherapist**
Kate Lippiett, University of Southampton/Bristol, **Nurse**
Ian Maidment, Aston University, **Pharmacist**
Ruben Mujica-Mota, University of Exeter, **Health Economist**
Barbara Nicholl, University of Glasgow, **Epidemiologist**
Reena Patel, Leeds Health and Care Partnership, **Pharmacist**
Samuel Relton, University of Leeds, **Statistician**
Susan Shenkin, University of Edinburgh, **Geriatrician**
Christine Smith, **Public Involvement Lead**
Krystal Warmoth, Queen Mary's University London, **Psychologist**

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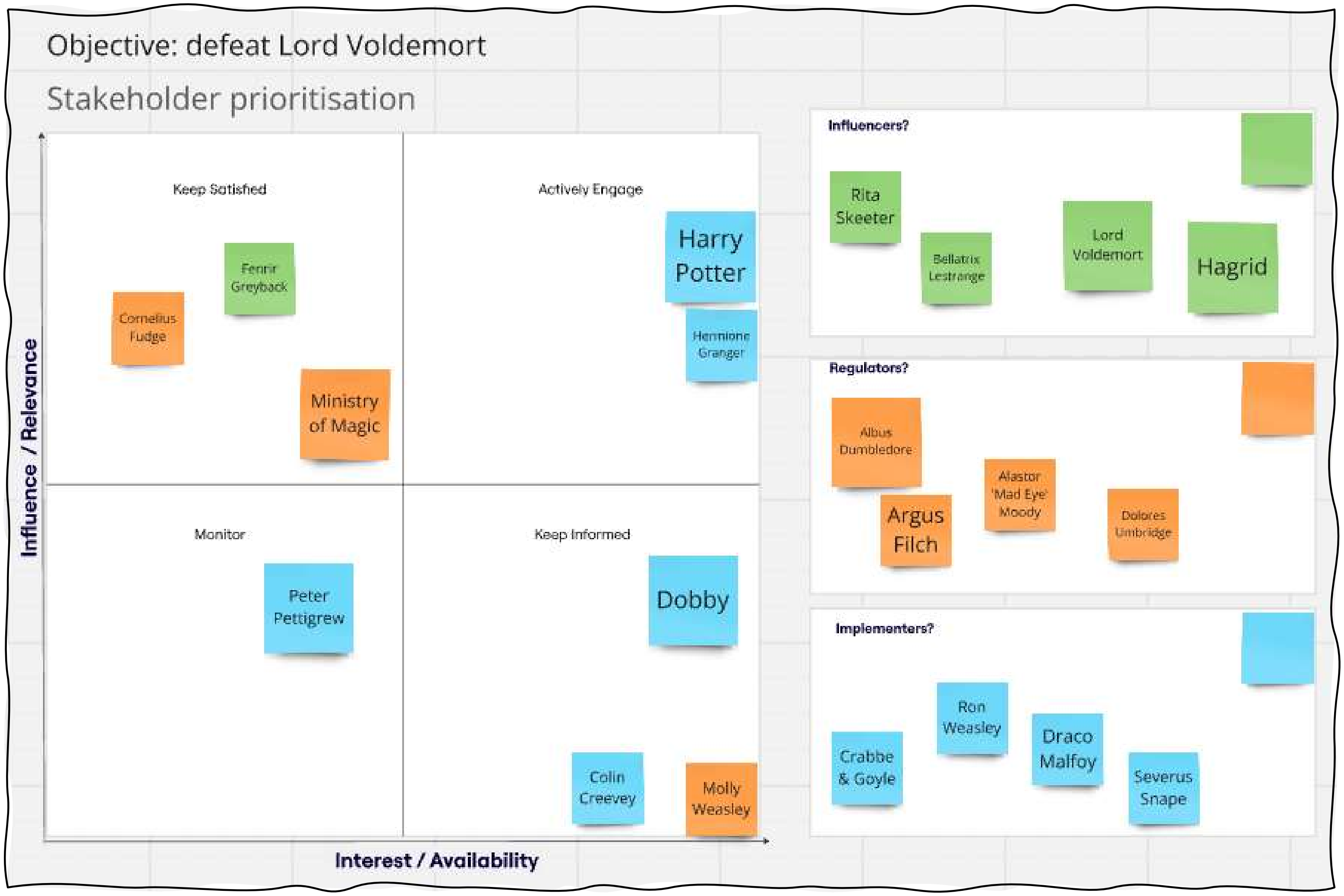
Models of Care – Team Science project delivery

Jan ‘25- Dec ‘26

Kamaldeep Bhui, University of Oxford, Epidemiologist, Psychiatrist
Pete Bower, University of Manchester, Health services researcher
Jo Butterworth, University of Exeter, GP – **Team Science lead**
Steve Callaghan, Patient and Public Representative
Andrew Clegg, University of Leeds, Geriatrician
Felicity Dewhurst, Newcastle University, Palliative Medicine
Hilary Garrett, Patient and Public Representative
Vicki Goodwin, University of Exeter, Physiotherapist
Rachel Johnson, University of Bristol, GP
Kate Lippiett, University of Southampton/Bristol, Nurse
Ian Maidment, Aston University, Pharmacist
Ruben Mujica-Mota, University of Exeter, Health Economist
Barbara Nicholl, University of Glasgow, Epidemiologist
Reena Patel, Leeds Health and Care Partnership, Pharmacist
Samuel Relton, University of Leeds, Statistician
Susan Shenkin, University of Edinburgh, Geriatrician
Christine Smith, Public Involvement Lead
Krystal Warmoth, Queen Mary’s University London, Psychologist

‘Team’ Science

Workstream MLTC MoC activities	Methodological & skills training
• Identification of gaps in membership • Position paper • Team building activities • e.g. ‘Harry Potter’ stakeholder mapping, Lego serious play • RJ & AC - CNC representation/feedback • Industry engagement event	• Scoping review training • Survey design training • Inclusive practices (EastARC re EqIA) • Industry & policy engagement • Undergrad intern (supervisory opportunity)



Objective: defeat Lord Voldemort

Stakeholder prioritisation

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Harry Potter character descriptions Link to **Miro** (via email)

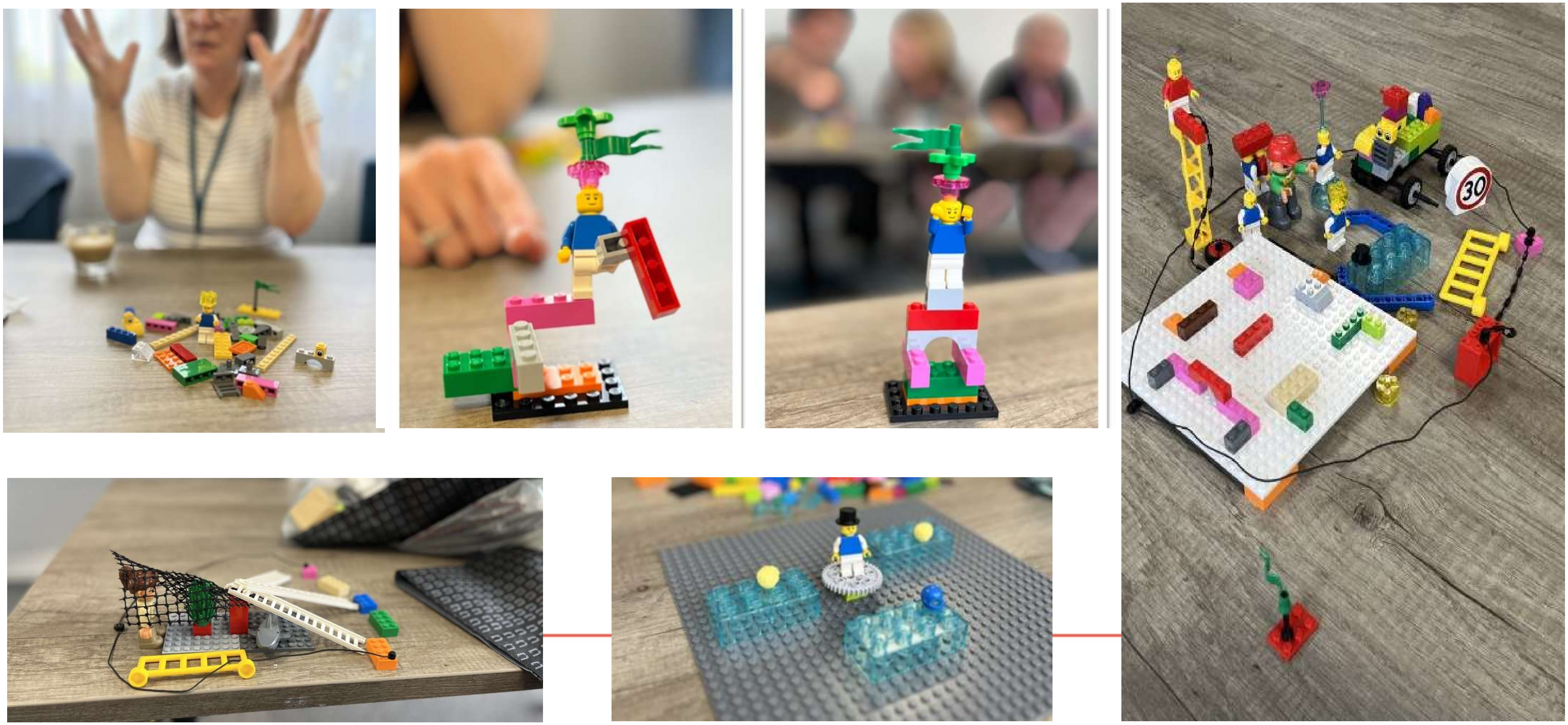
Review the objective (defeat Voldemort), prioritise ‘stakeholders’

Split into three groups, consider the colour coding: Influencers? Regulators? Implementers?

Place ‘stakeholders’ onto the matrix

Team Building – Harry Potter stakeholder mapping

Team Building – Lego Serious Play



Stakeholder identification

- Create a database / ‘map’ of
    - who is involved in developing, delivering and implementing MoC for MLTC
    - where they do it
    - what resources they require


Stakeholders
Influencers
Regulators
Implementers
Keep Satisfied
Actively Engage
Monitor
Keep Informed
Influence / Relevance
Interest / Availability
Director of Community Care at NHSE
NHSE …ctor of …onalised Care
UK Parliament Knowledge Exchange Unit
Community health orgs
royal colleges e.g. RCGP
Local Authorities
ICSs
ARCs
EPSRC
NHS Confederation
CNC MLTC PPIE network
NIHR policy units
NIHR centre for engagement and dissemination (INVOLVE as was)
Richmond group of charities
Director of HSDR programme
Generic patient groups e.g. National Voices
Media?
Use my data
THIS Institute
King's Fund
Nuffield Foundation
Health Foundation
Chief Scientist Office (Scotland)
Department of Health and Social Care, NHS England
Public Health Agency - NI
Rowntree Foundation
NIHR ARC PIC - PPIE Leads network
TPP and EMIS
Shaping Our lives - head of projects
…mmunity …abilitation …lliance
…SSCR - Director
Other cross NIHR workstreams
ICB and Health and Care Boards
SDSMIC
local NIHR Knowledge Mobilisation …
Hospice UK
NIHR - SPCR - Assistant Director
Medical Research Foundation
MHRA
National Care service
OpenSAFELY
Commercial?
Secure Data Environments
NIHR - Mental Health Incubator - coordinator
MQ
Industry?
Pharma
Dean of NIHR Academy
Versus Arthritis
NICE
SIGN
Nuffield Trust
Association of Directors of Public Health
SAPC
NIHR community rehabilitation incubator
…of Health Improvement & Disparities
British Genetics Society
ADASS
Integrated Care Foundation

Our stakeholder expertise includes:

- Department of Health and Social Care (DHSC) regulation and policy
- Public health policy
- National Institute for Health and Care Excellence (NICE)
- Integrated Care Boards (ICBs)
- Health Innovation Networks (HINs)
- NHS health and social care management and infrastructure
- Independent consultancy in equitable healthcare
- Clinical expertise, including health, allied health and social care
- Voluntary and charitable organisations and enterprises (VCSEs), including social care
- Patient and carer advocacy
- NIHR research management
- Industry, including digital health care
- Interdisciplinary research, including economic and social research, relevant methodologies including data science

Stakeholder engagement activities:

- Engagement meetings 4x 2hr joint meeting (June x2 and Oct x2) with ~10 reps in each

1. Intros to the project
    - Sought priorities for research (presented Lego play model & invited discussion)
    - Asked whether those attending could disseminate the survey to their networks
    - Invited to be on our PSP steering group

2. Feedback sought on
    - Scoping review
        - presentation & dissemination of findings (e.g. narrative, infographics, inequalities)
        - discussion of PSP survey reach and dissemination - offers of help to reach underserved

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Stakeholder engagement

Industry-NHS-academic collaboration:
MLTC CNC event, Leicester, Nov ‘25

Patient and public involvement (PPI)

- Shaped by National Standards for Public Involvement
- National diverse group, convened by CS, through advertising and interviews (20 members)
- PPI reps on the CNC for MLTC MoC workstream and on PSP steering group
- Influence direction and interpretation of the research
- Impact Log (PIRIT template)

Patient and public involvement (PPI)

- 4 x 2-hour meetings joint with the ACCORD project team - April, June, August, October.

  1. Intros. We asked: “What does good care look like? When care worked well what made the difference? What is the one thing to research?”
  2. Deeper dive: Defining and implementing ‘good care’
  3. Informed the EqIA: Themes from ‘my diagnostic odyssey’ creative prep work. Suggested routes of priority-setting survey dissemination.
  4. Planning for industry engagement event, update on scoping review and reviewed perspectives on survey design, content, ongoing EDI considerations

- Research inclusion bid – for submission Dec ’25
- Next PPI activity will be online – to review the first draft PSP survey

PPI perspectives “Good care…

- is person- and family-centred with collaborative decision-making
- understands co-existing conditions and their interactions
- recognises the individual (beyond their conditions) and includes ‘lifestyle care’
- adopts holistic, inclusive approaches to respect patients’ lived experiences, e.g. language, and avoid stereotyping
- includes carers as vital partners to enable timely decisions, plan ahead, maintain dignity
- is coordinated and consistent across services: primary, secondary, social, and voluntary sectors (as well as private care)
- empowers staff to share core values, to work beyond rigid roles, to provide flexible, tailored care and avoid generic (AI) algorithms
- includes good communication (including training for professionals), considers health literacy and being given enough time
- has a single point of contact, avoids fragmentation, repetition, and long ‘demoralising’ waits, and ensures continuity
- uses technology to
  - improve communication between and integration of health and social care, including sharing of health records
  - make systems more responsive and personalised whilst avoiding digital exclusion
- addresses emotional and practical needs (of both patients and carers)
- is both effective and compassionate
- improves quality of life
- reduces social isolation
- reduces inappropriate medication and addresses polypharmacy, with likely financial benefit to the healthcare system
- enables proactive work culture, with supportive team working

”

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Existing evidence – scoping review

✓OSF | Models of Care for Individuals Living with Multiple Long-Term Conditions: Scoping Review Protocol

Objective: examine research to date, and identify knowledge gaps in relation to MoC for MLTC

Rationale: limited evidence to guide research priority-setting that reflects perspectives of key stakeholders (patients, carers, policymakers, commissioners) & equitably meets needs of patients

Inclusion criteria: International literature, global models of care for individuals with MLTC and data from perspective of key stakeholders. Studies on single long-term conditions excluded.

Methods: JBI methodology. Key databases including MEDLINE (Ovid), CINAHL, and Cochrane Library. Independent reviewers for screening and extraction. Synthesis summarised in tabular and narrative format.

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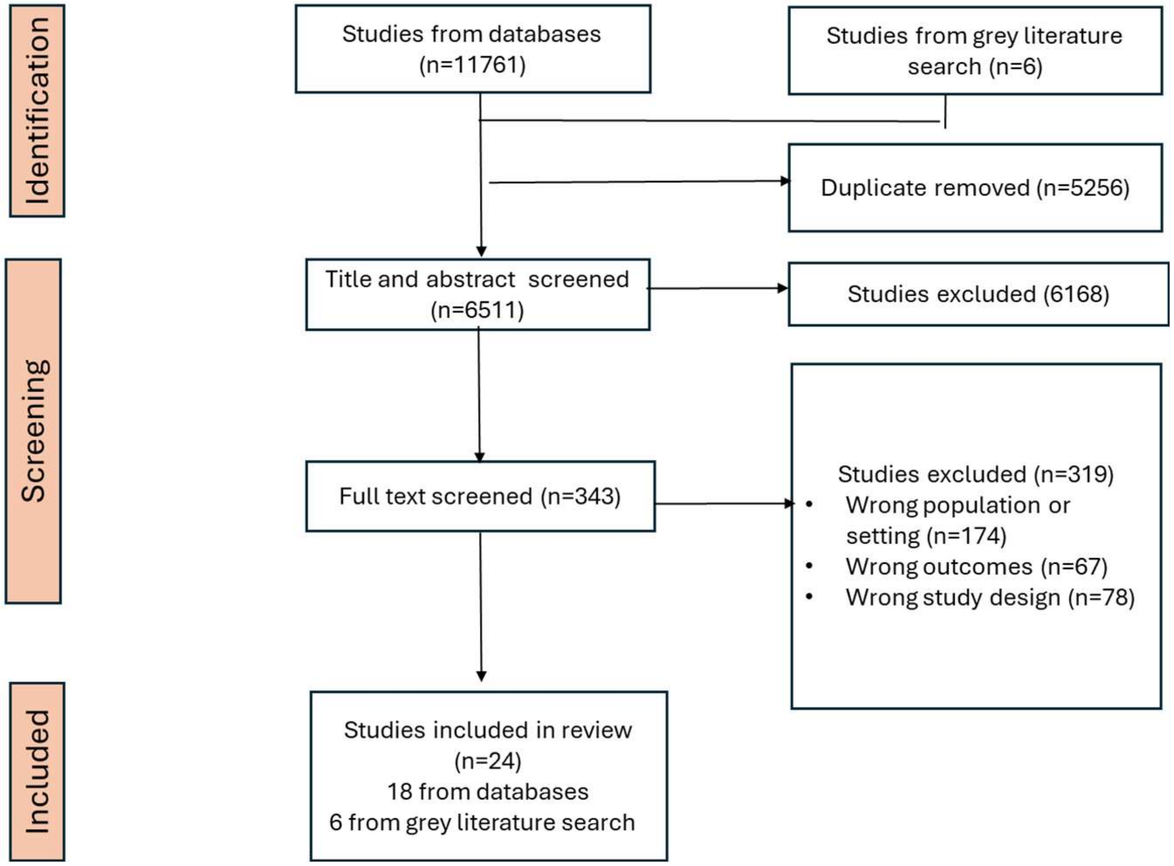
Existing evidence – scoping review findings



Studies from databases (n=11761)

Studies from grey literature search (n=6)

Duplicate removed (n=5256)

Title and abstract screened (n=6511)

Studies excluded (6168)

Full text screened (n=343)

Studies excluded (n=319)
- Wrong population or setting (n=174)
- Wrong outcomes (n=67)
- Wrong study design (n=78)

Studies included in review (n=24)
18 from databases
6 from grey literature search

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Existing evidence – scoping review findings:

Sources of data (n = 24)

- Peer reviewed papers (n=18)
  - Quant (n=5)
  - Qual (n=3)
  - DCE (n=3)
  - Mixed (n=2)
- Grey literature (n=6)
  - Report (n=3)
  - Review (n=2)
  - Survey (n=1)

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Data extraction – now to map!

Stakeholder representation

- Patients
- Carers
- HCPs
- Academics
- Policy makers
- Social workers

Setting

- Primary
- Community
- Secondary
- Social care
- Mixed

Structural elements of MoC

- Infrastructure
- Workforce
- Coordination
- Person centred

Context of research priorities

- Workforce shortage & training
- Governance & funding
- Data-driven solutions
- Vulnerable populations
- Care coordination

Scoping review next steps

- Mapping and narrative synthesis of extracted data
- Visual representation of analysis (with PPI and stakeholder input)
- Reporting to include a focus on ‘missing voices’ to further inform the EqIA and the PSP

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Equality Impact Assessment (EqIA)

✓Drafted our first EqIA plan, through

A six-week undergrad summer placement (NIHR ECR-led)
  ✓review of literature
  ✓engagement with East Midlands ARC team (advisory/guidance meeting)
  ✓PPI meeting utilising creative activities “draw your Diagnostic Odyssey”
  ✓Stakeholder meeting

Outputs so far:
✓Blog Equality Considerations in Multiple Long-Term Conditions Research
✓draft poster and swSAPC conference abstract

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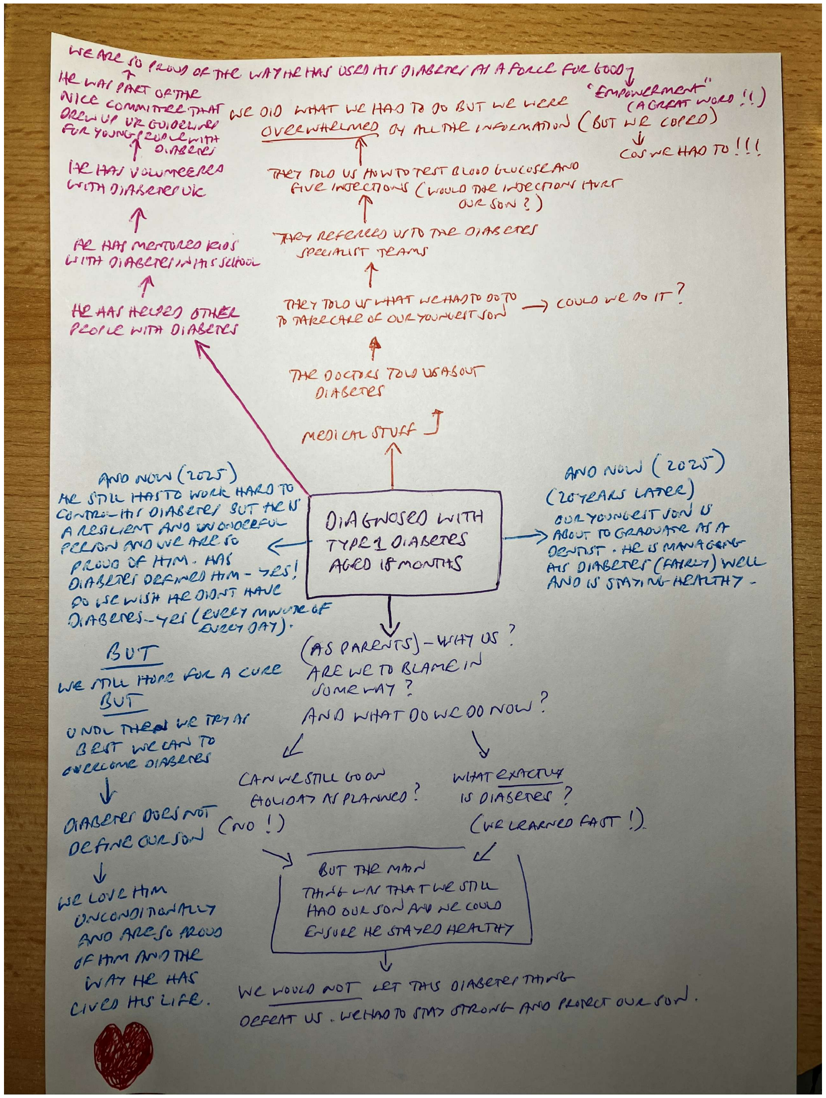


WE ARE SO PROUD OF THE WAY HE HAS USED HIS DIABETES AS A FORCE FOR GOOD

"EMPOWERMENT" (A GREAT WORD !!)

HE WAS PART OF THE NICE COMMITTEE THAT DREW UP UK GUIDELINES FOR YOUNG PEOPLE WITH DIABETES

HE HAS VOLUNTEERED WITH DIABETES UK

HE HAS MENTORED KIDS WITH DIABETES IN HIS SCHOOL

HE HAS HELPED OTHER PEOPLE WITH DIABETES

WE DID WHAT WE HAD TO DO BUT WE WERE OVERWHELMED BY ALL THE INFORMATION (BUT WE COPED)

COS WE HAD TO !!!

THEY TOLD US HOW TO TEST BLOOD GLUCOSE AND GIVE INJECTIONS (WOULD THE INJECTIONS HURT OUR SON ?)

THEY REFERRED US TO THE DIABETES SPECIALIST TEAMS

THEY TOLD US WHAT WE HAD TO DO TO TO TAKE CARE OF OUR YOUNGEST SON → COULD WE DO IT ?

THE DOCTORS TOLD US ABOUT DIABETES

MEDICAL STUFF

DIAGNOSED WITH TYPE 1 DIABETES AGED 18 MONTHS

AND NOW (2025) HE STILL HAS TO WORK HARD TO CONTROL HIS DIABETES BUT HE IS A RESILIENT AND WONDERFUL PERSON AND WE ARE SO PROUD OF HIM. HAS DIABETES DEFINED HIM – YES! DO WE WISH HE DIDN'T HAVE DIABETES – YES (EVERY MINUTE OF EVERY DAY).

AND NOW (2025) (20 YEARS LATER) OUR YOUNGEST SON IS ABOUT TO GRADUATE AS A DENTIST. HE IS MANAGING HIS DIABETES (FAIRLY) WELL AND IS STAYING HEALTHY –

BUT

WE STILL HOPE FOR A CURE

BUT

UNTIL THEN WE TRY AS BEST WE CAN TO OVERCOME DIABETES

↓

DIABETES DOES NOT DEFINE OUR SON

↓

WE LOVE HIM UNCONDITIONALLY AND ARE SO PROUD OF HIM AND THE WAY HE HAS LIVED HIS LIFE.

(AS PARENTS) – WHY US ? ARE WE TO BLAME IN SOME WAY ?

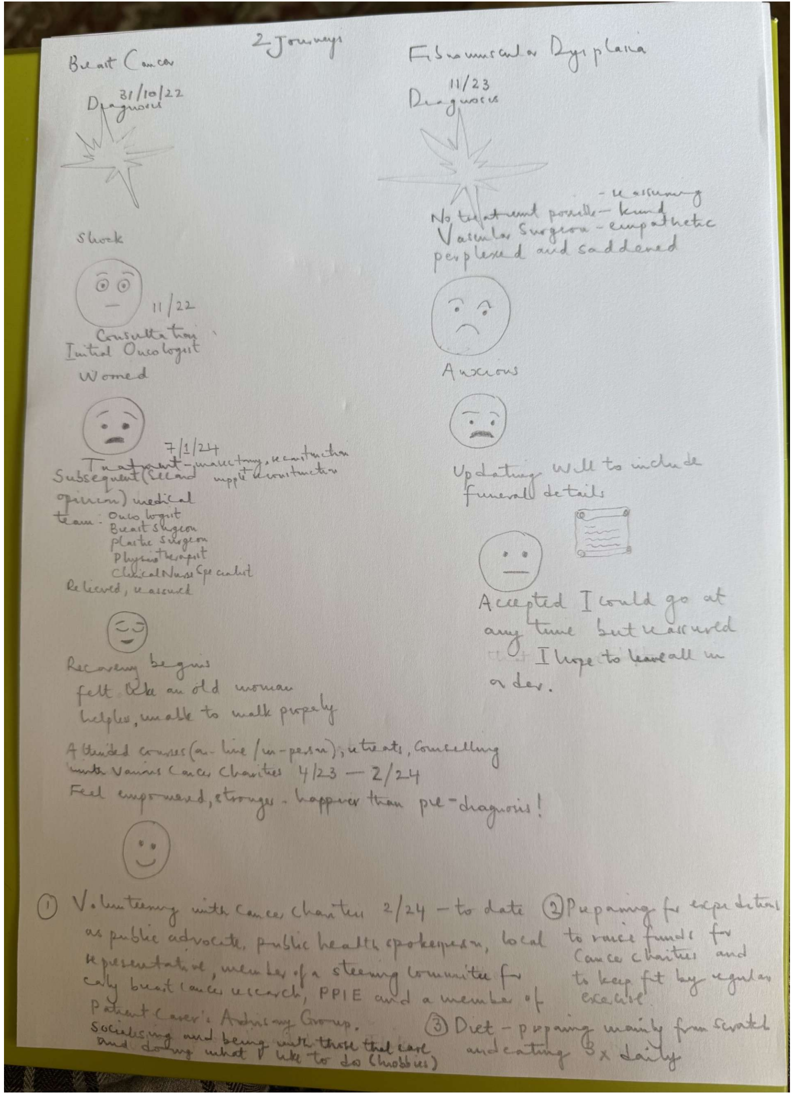
AND WHAT DO WE DO NOW ?

CAN WE STILL GO ON HOLIDAY AS PLANNED ? (NO !)

WHAT EXACTLY IS DIABETES ? (WE LEARNED FAST !)

BUT THE MAIN THING WAS THAT WE STILL HAD OUR SON AND WE COULD ENSURE HE STAYED HEALTHY

WE WOULD NOT LET THIS DIABETES THING DEFEAT US. WE HAD TO STAY STRONG AND PROTECT OUR SON.



2 Journeys

Breast Cancer

31/10/22 Diagnosis

Shock

11/22 Consultation Initial Oncologist

Worried

7/1/24 Treatment – mastectomy, reconstruction + nipple reconstruction

Subsequent (second opinion) medical team: Oncologist
Breast Surgeon
plastic Surgeon
Physiotherapist
Clinical Nurse Specialist

Relieved, reassured

Recovery begins
felt like an old woman
helpless, unable to walk properly

Attended courses (on-line / in-person); retreats, Counselling with various Cancer Charities 4/23 — 2/24

Feel empowered, stronger – happier than pre-diagnosis!

Fibromuscular Dysplasia

11/23 Diagnosis

No treatment possible – kind – reassuring Vascular Surgeon – empathetic

perplexed and saddened

Anxious

Updating will to include funeral details

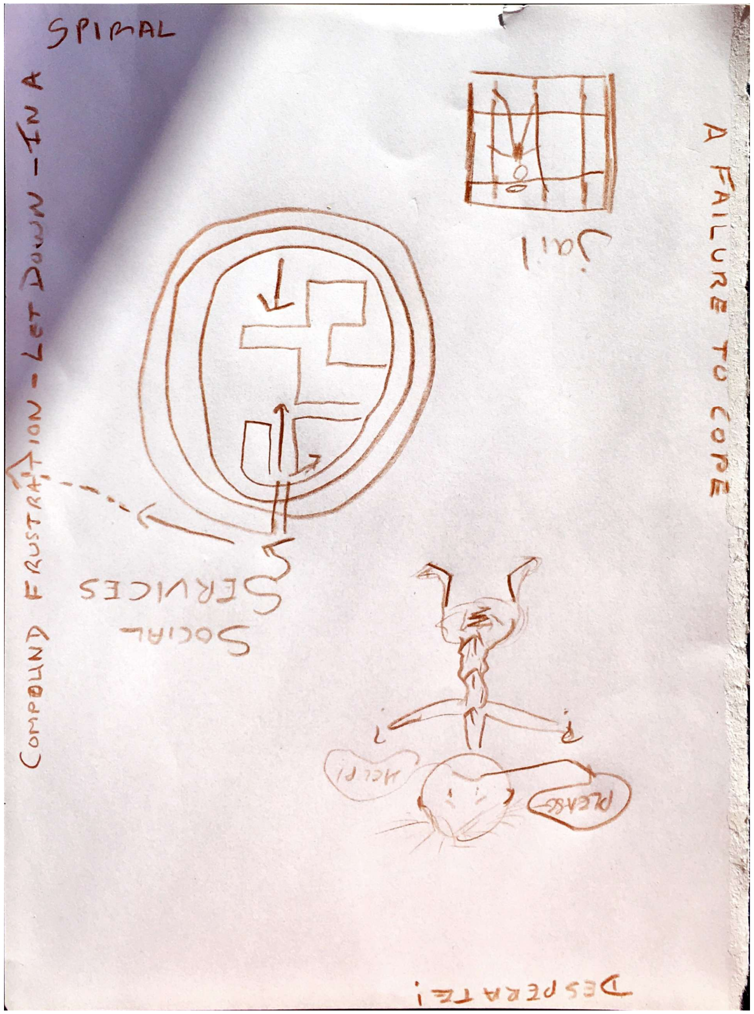
Accepted I could go at any time but reassured I hope to leave all in order.

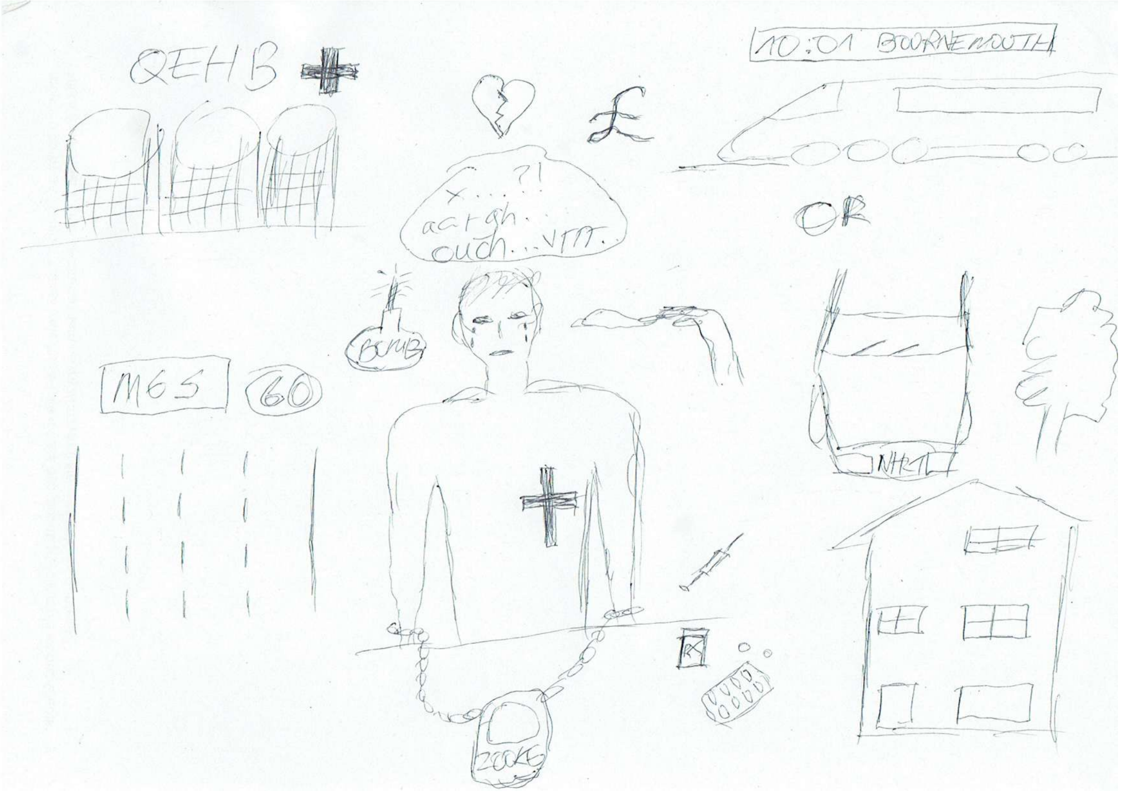
① Volunteering with Cancer Charities 2/24 – to date as public advocate, public health spokesperson, local representative, member of a steering committee for early breast cancer research, PPIE and a member of Patient Carer's Advisory Group.

② Preparing for expeditions to raise funds for Cancer charities and to keep fit by regular exercise

③ Diet – preparing mainly from scratch and eating 3x daily

Socialising and being with those that care and doing what I like to do (hobbies)


SPIRAL
COMPOUND FRUSTRATION - LET DOWN - IN A SPIRAL
A FAILURE TO COPE
Jail
SOCIAL SERVICES
HELP!
PLEASE
DESPERATE!


QEHB
10:01 BOURNEMOUTH
£
x....?!
aargh.
ouch...!!!!.
OR
BOMB
M65
60
Rx
ZOOKE

When I Speak

I speak,
but the words fall into cracks
between departments,
between tick-box forms and
tired eyes.

I carry more than one label —
each a story,
each a scar —
yet they are read one at a time,
as if the rest of me waits in
another file.

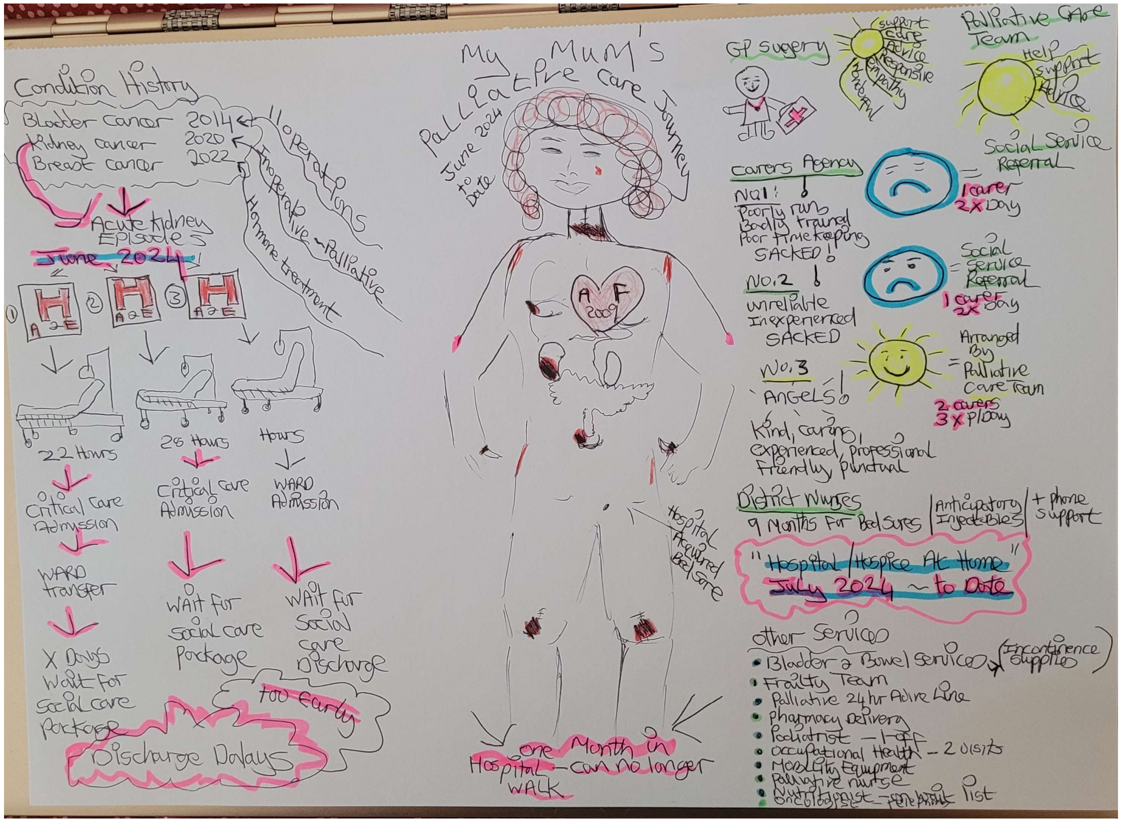
My body is a map of long
journeys:
strokes and surgeries,
arthritis mornings,
Addison's nights,
the unending ache of care
wrapped around love.

I speak again,
but the sound is muffled
by policy,
by time limits,
by the quiet assumption
that complex means
complicated means too much.

No one sees the whole of me
unless they have lived
with many threads tangled in
the same cloth.

Still, I speak,
because silence feels heavier
than all my conditions
combined.

And one day,
someone will listen
not to the illness in my voice,
but to the person who carries it



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Equality issues identified for our PSP by the EqIA

Some examples:

- Access to diagnosis
- Exclusion of working age adults with MLTC
- Recognition and understanding of non-standard and community-developed care
- Distrust of medical systems / medical research preventing participation
- Inaccessibility of survey materials
- Underrepresentation and / or unintentional exclusion of marginalised community members

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Proposed PSP action plan from EqIA

- Survey invite to contain screening information to **enable eligible participants to self-identify**
  - even if they are undiagnosed but experiencing complex, multisystemic symptoms of MLTC
  - be clear that a person does not need to view themselves as a carer to be included
  - patient and carer roles are not mutually exclusive
- Prepare large text, **paper** copy and **Easy Read** versions of information sheets and surveys
- Ensure **digital** versions are compatible with **screen readers** and available in **large text** format
- Avoid unintentionally discriminatory **language** (e.g. 'non-binary') in demographic data questions
  - Avoid gendered language wherever possible (e.g. 'pregnant person' not 'pregnant woman')
- Convey that the **research intention** is to be non-extractive, instead a **respectful partnership**
- Identify **partners** (through PPI and stakeholder engagement) to specifically support recruitment of **underserved groups** with MLTC e.g. working age /young&disabled, men, intersex, trans and queer people
- Identify if **translation** of survey materials is needed and into which specific languages
- Identify locations where **individuals who do not access ICT** (e.g. bedbound/housebound individuals) reside and utilise **in-person recruitment** in those places
- Clarify that having **another person complete the form** with the participant's answers is acceptable

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Proposed EqIA monitoring and evaluation efforts

- Collect demographic data from participants
- Track outcomes of recruitment efforts to access underrepresented communities
- Compare study sample to known demographics of UK

- Work with PPIE group and steering group to ensure there are not oversights in recruitment, study design or analysis

Moving forward - Year 2: Priority-setting partnership (PSP)

✓[OSF | Models of Care for Individuals Living with Multiple Long-Term Conditions Priority Setting Partnership PROTOCOL]

✓Steering group set up

✓Ongoing stakeholder and PPI involvement

PSP steering group: Governance and oversight

- **Composition**
- 13 members, diverse geographically and by personal characteristics. Many bring more than one perspective and/or relevant lived experience. This includes:
- **Patient advocates** with lived experience of MLTC or **caregivers** for someone with MLTC
- **Health and social care practitioners** (including nursing, midwifery, dental, pharmacy, physiotherapy and social prescribing perspectives)
- Experience of **health services management**, including in the context of social deprivation e.g. homelessness
- Representation from **voluntary and community organisations and social enterprises** (VCSE)
- Health service **commissioning** expertise
- Health research **funding** expertise

- **Independent Chair:**

  Patient and public representative

- **Role**
  - Oversee the PSP activities
  - Make final decisions regarding research priorities and methodologies
  - Ensure the PSP adheres to core principles of transparency and inclusivity

Five steps for Systematic Priority Setting (steps 1-3):

✓**Step 1: Identification of potential partners,** target underrepresented groups

✓**Step 2: Awareness raising activities** e.g., stakeholder and PPI workshops

Step 3: Identifying unanswered questions
- ✓comprehensive scoping review
- ☐online survey to gather unanswered questions, with targeted outreach
  - ✓Advice re. ethical approvals from UoE

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Five steps for Systematic Priority Setting (steps 4–5):

Step 4: Refining questions

- ☐survey responses collated, categorised and refined

Step 5: Prioritisation

- ☐**Interim:** Second survey to rank the refined questions (~25 questions)
- ☐**Final:** Priority-setting workshops using the nominal group technique

☐Identify **'top 10' research priorities for Models of Care for MLTC**

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The steering group involvement – timeline of activities

✓November 2025: **First steering group meeting**

January 2026: **Second steering group meeting**

- ☐Develop first survey

February – March 2026: First survey open

April – May 2026: **Third steering group meeting**

- ☐Review first survey results

June 2026: **Online collaborative working with steering group**

- ☐Agree on second survey

June – July 2026: Second survey open

September 2026: **Fifth steering group meeting**

- ☐Review second survey results, prepare for consensus meeting

October 2026: **Consensus meeting**

- ☐Half day meetings to translate findings into tractable questions (reps from ICBs etc)

Dissemination planning

✓Website https://sites.exeter.ac.uk/mltc-models-of-care/ including plain language summaries and PPIE / stakeholder engagement blog

☐Public-facing materials (infographics)

☐Conferences –
  ✓scoping review swSAPC abstract
  ✓EqIA swSAPC abstract
  ☐PSP (include PPI) ?national SAPC

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Future steps

- Take forward at least one research priority
  - Grant / fellowship applications
- Translate the findings of the PSP into policy and practice
  - NHS 10-year plan and implementation plan
- Improve models of care for
  - individuals from diverse backgrounds living with MLTC, their caregivers, practitioners, the system

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