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VIA VERITAS VITA
Missingness in healthcare, importance, causes and solutions
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WORLD CHANGING GLASGOW
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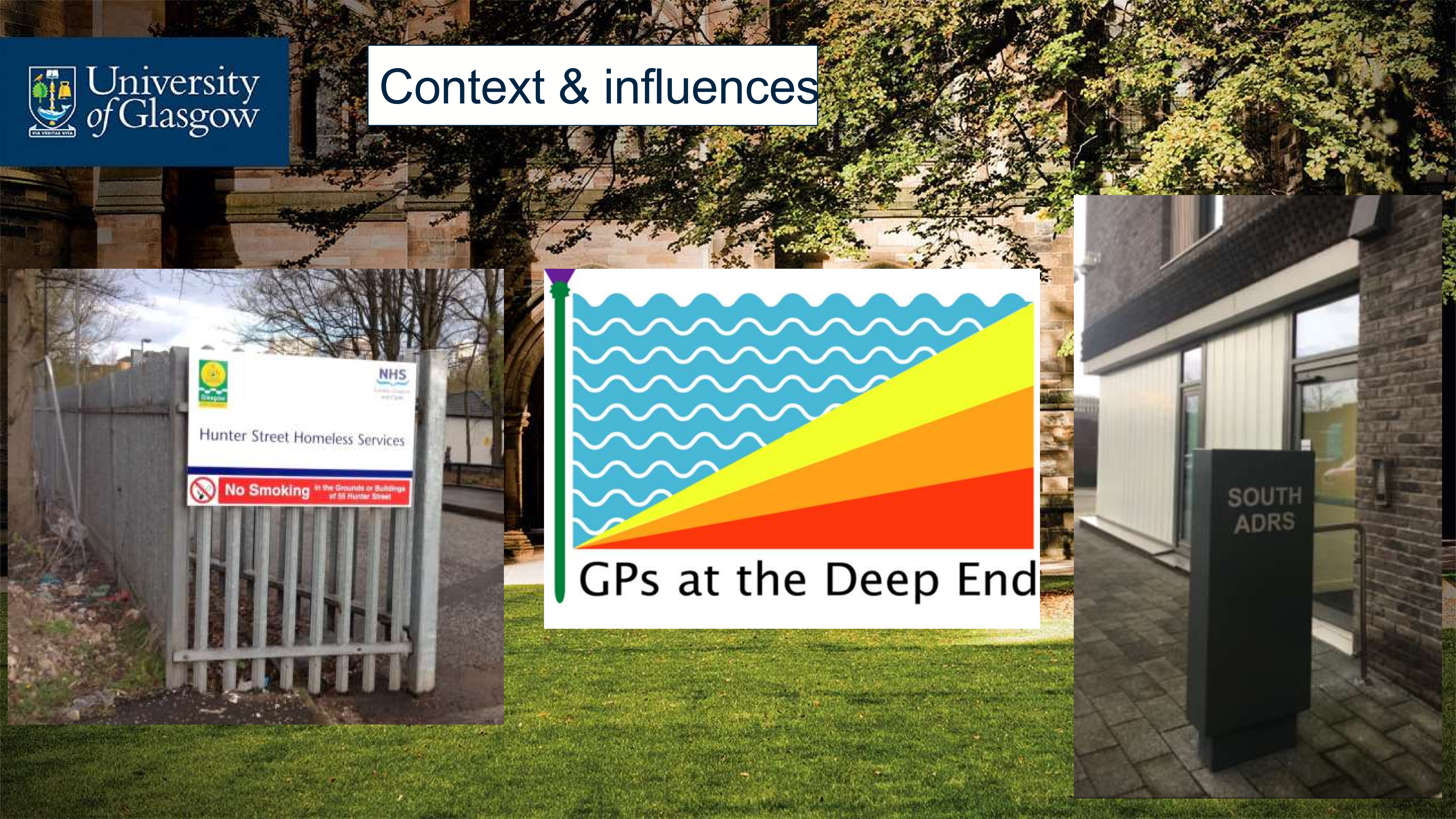
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Context & influences
NHS
Hunter Street Homeless Services
No Smoking
GPs at the Deep End
SOUTH
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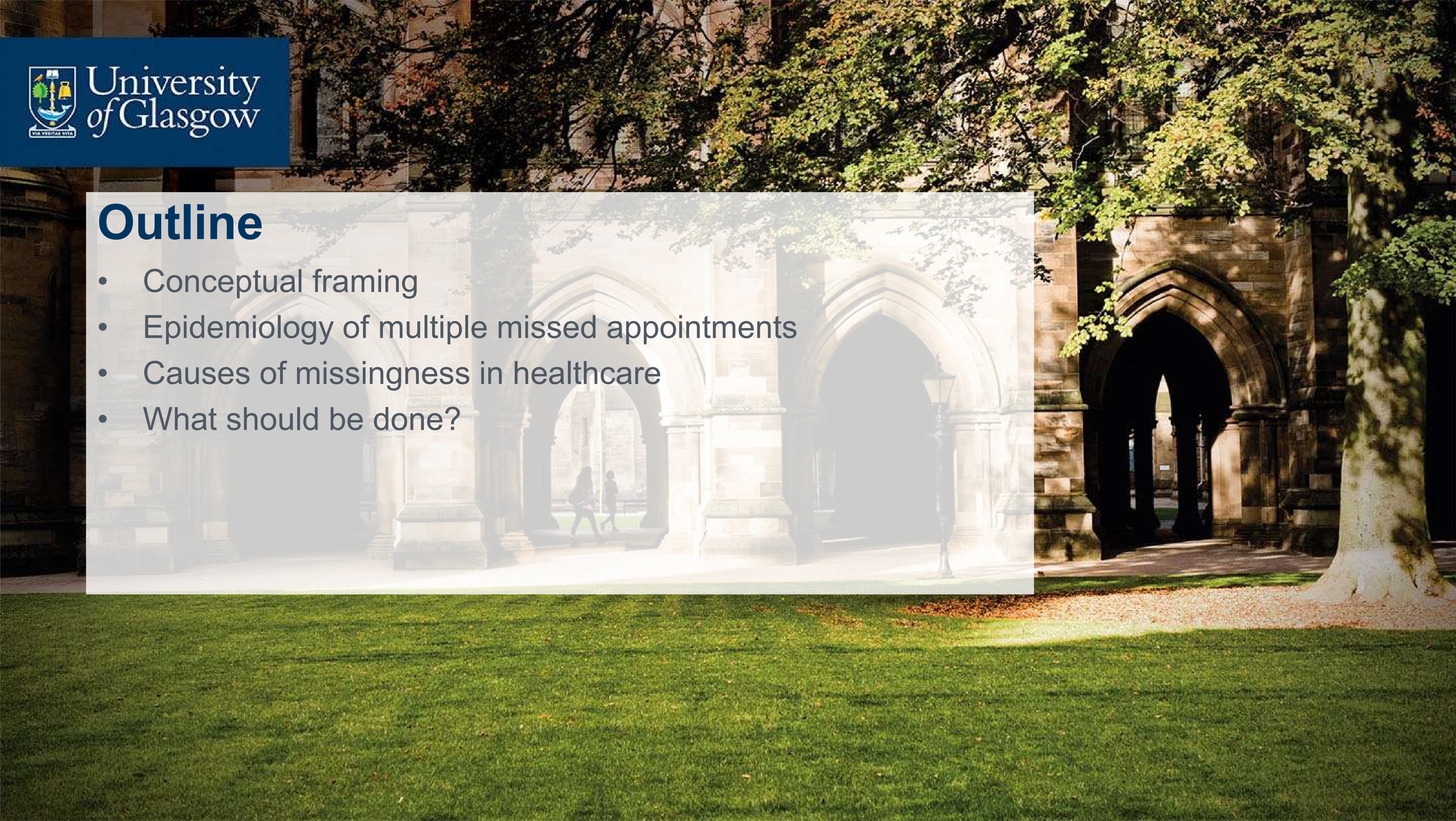
Acknowledgement
I acknowledge the survivorship of the people who are in Inclusion Health groups and who I meet and represent in my work. They continue to be an inspiration to me through their resilience and strength in the face of adversity.



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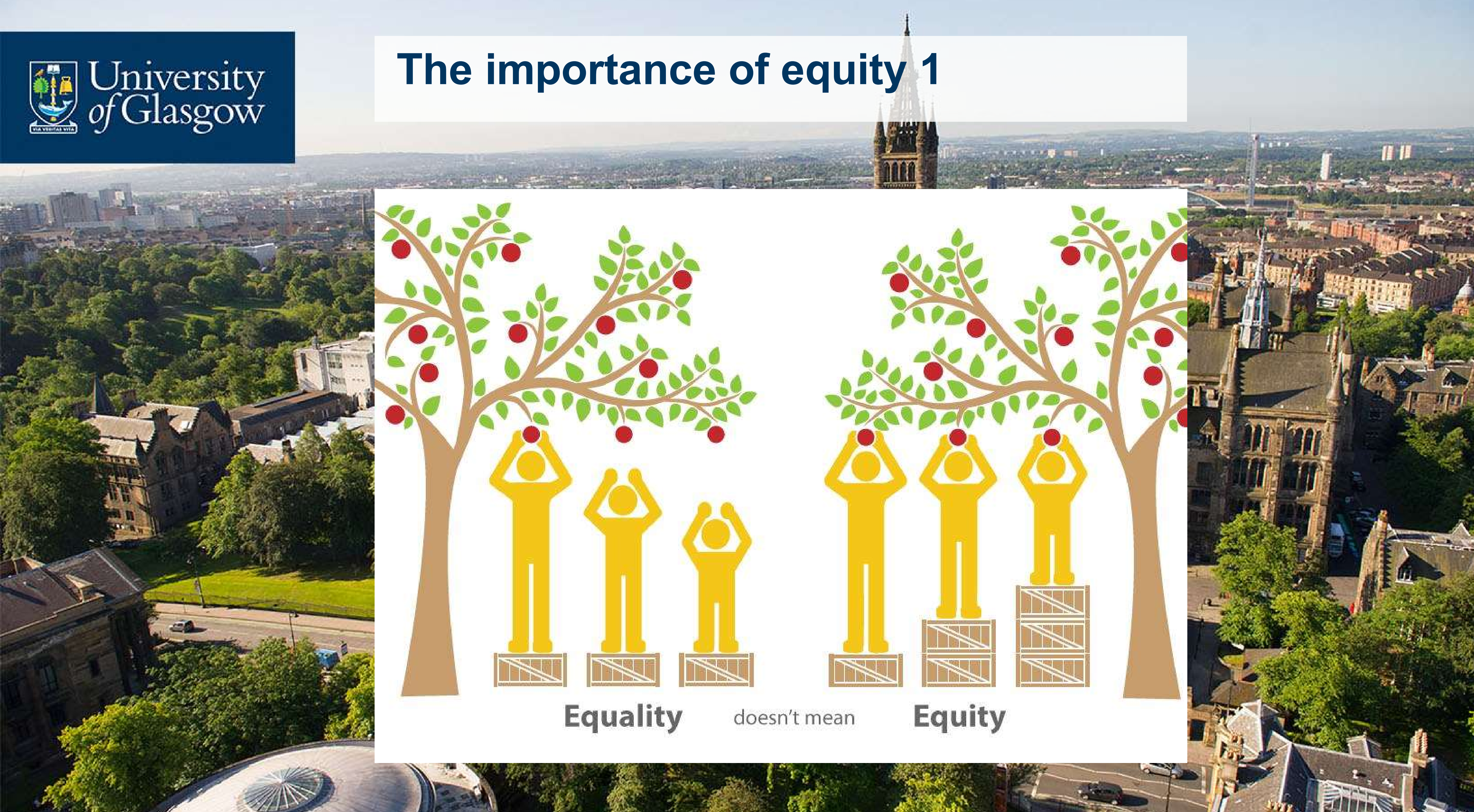
Outline
• Conceptual framing
• Epidemiology of multiple missed appointments
• Causes of missingness in healthcare
• What should be done?

Definition of Inclusion Health populations

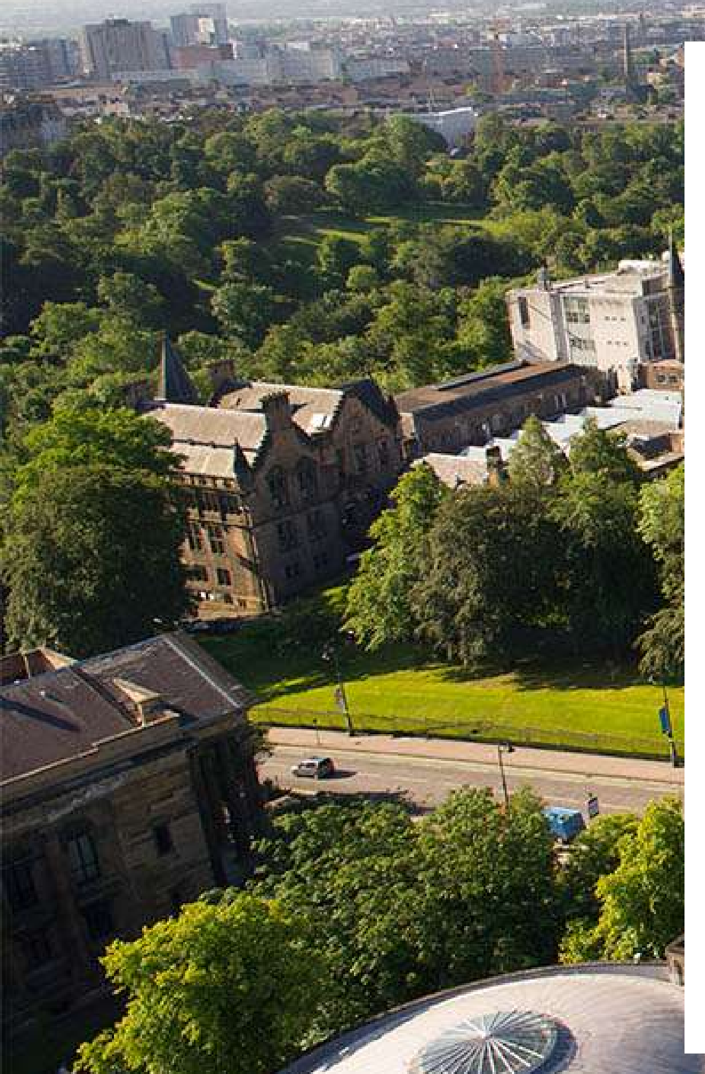
"people who are socially excluded, typically experience multiple overlapping risk factors for poor health (such as poverty, violence and complex trauma), experience stigma and discrimination, and are not consistently accounted for in electronic records (such as healthcare databases). These experiences frequently lead to barriers in access to healthcare and extremely poor health outcomes."

(Public Health England 2021)

The importance of equity 1



The importance of equity 2



The impact of the SDHs on treatment burden

Source: *Making Partners: Intersectoral Action for Health* 1988 Proceedings and outcome of a WHO Joint Working Group on Intersectoral Action for Health, The Netherlands.

Defining ‘Missingness’

*“The **repeated tendency** not to take up opportunities for care, such that it has a **negative impact on the person** and their life chances”*

(Lindsay et al, 2023)

- Not one or two, but multiple missed appointments over an extended period of time
- Signifies **significant and enduring challenges** in accessing and engaging in healthcare

SMA Research Acknowledgements

Co-investigators: David A Ellis, Alex McConnachie & Phil Wilson

Researcher: Ross McQueenie

Collaborator: Mike Fleming

Trusted Third Party: Dave Kelly Albasoft

Participating GP practices

Colleagues at Scot Gov and eDRIS

Serial Missed Appointments study definition

Average of general practice face to face appointments over previous **three years**

- **Never missed appointments per year, 0**
- **Low missed appointments per year, <1**
- **Medium missed appointments per year, 1-2**
- **High missed appointments per year, 2 or more**

(Williamson et al BMJ Open 2017)

Missed appointments results

136 Scottish representative GP practices

550 083 patient records

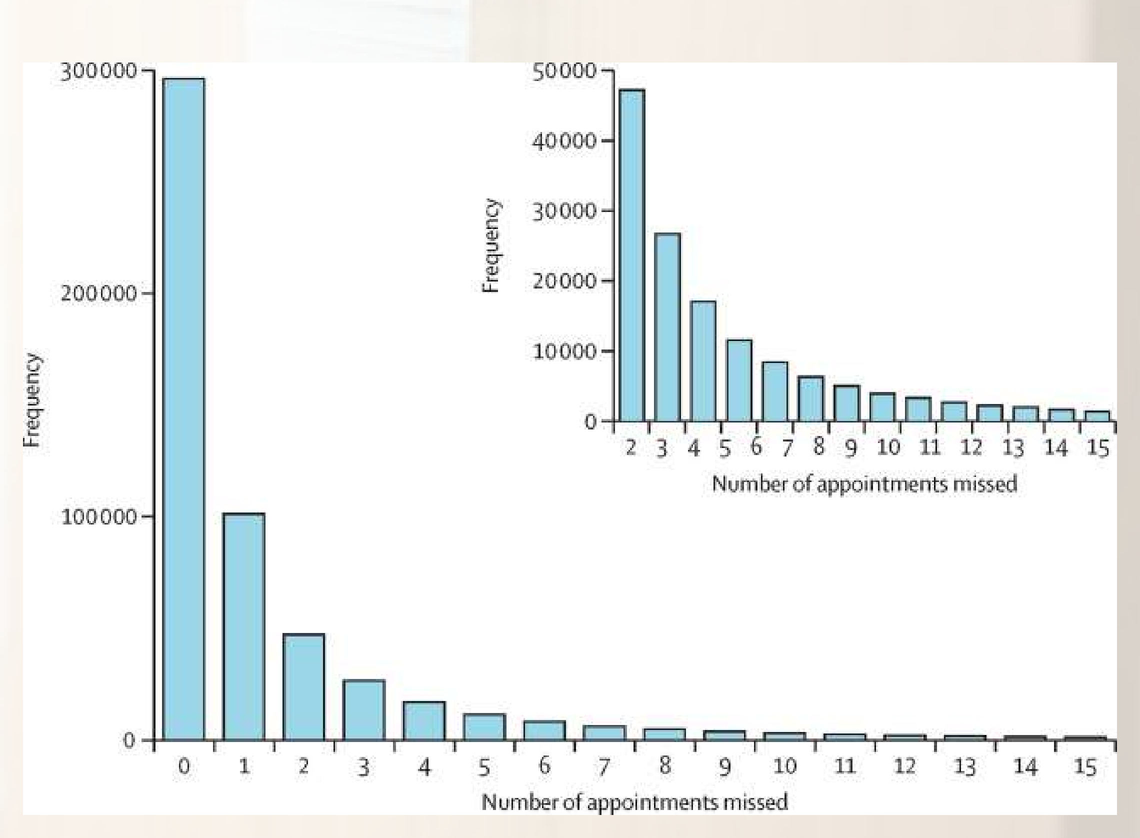
9 177 054 consultations

54·0% (297,002) missed no appointments

46·0% (212,155) missed one or more appointments

19·0% (104,461) missed more than two appointments

(Ellis, McQueenie et al Lancet Public Health 2017)



Patient demographic factors

- Most socio-economically deprived **(SIMD 1)** patients most likely to miss appointments (RRR 2·27, 95% CI 2·22–2·31)
- Most remotely located patients least likely to miss appointments (RR 0.37, 0.36–0.38)
- Patients aged **16–30 years** (1·21, 1·19–1·23) & **older than 90 years** (2·20, 2·09–2·29) more likely to miss appointments
- Effect of gender small
- Ethnicity poorly recorded (2.69% all records)

(Ellis, McQueenie et al Lancet Public Health 2017)

GP practice demographic factors

- **Appointment delay 2–3 days** (RRR 2·54, 95% CI 2·46–2·62) most strongly associated with non-attendance
- **Urban GP practices** more strongly associated with missed appointments
- **More SE deprived patients registered with GP practices in more affluent settings have the highest risk of missing appointments**

(Ellis, McQueenie et al Lancet Public Health 2017)

Patient and practice demographics

- **Practice factors have a larger effect** than patient factors but a model combining both patient and practice factors gave a higher Cox-Snell pseudo R^2 value (0·66) than models using either group of factors separately (patients only R^2=0·54;practice only R^2=0·63) (Ellis, McQueenie et al Lancet Public Health 2017)

Morbidity and mortality

- Patients with **more long-term conditions** have increased risk of missing GP appointments (controlling for number of appts made)
- Patients missing appointments were at much greater risk of **all-cause mortality, the risk increasing with number of missed appointments** (independent of morbidities)

(McQueenie et al BMC Medicine, 2019)

Shocking mortality

- Patients with **long-term mental-health conditions missing >2 appointments per year had >8x** risk of all-cause mortality compared with those who missed no appointments
- These patients died at a **younger age**, and commonly from **non-natural external factors**
- **Missing appointments repeatedly seems to be a powerful marker for greatly increased risk of mortality, particularly among those <u>without</u> physical long-term conditions** (after adjustment for all other mortality risks)

(McQueenie et al BMC Medicine, 2019)

Risk of death

Cox regression: adjusted for age, sex, demographics, practice factors and number of long-term conditions (McQueenie et al BMC Medicine, 2019)

All cause mortality

Zero
Low
Medium
High

0 0.5 1 1.5 2 2.5 3 3.5 4
Hazard Ratio with 95% Confidence Intervals

All cause mortality for physical health conditions only

Zero
Low
Medium
High

0 0.5 1 1.5 2 2.5 3 3.5 4 4.5 5 5.5 6 6.5 7 7.5 8 8.5 9 9.5 10
Hazard Ratio with 95% Confidence Intervals

All cause mortality for mental health conditions only

Zero
Low
Medium
High

0 0.5 1 1.5 2 2.5 3 3.5 4 4.5 5 5.5 6 6.5 7 7.5 8 8.5 9 9.5 10
Hazard Ratio with 95% Confidence Intervals

Hospital utilization

- Patients missing **high numbers** of GP appointments were **higher users** of **hospital outpatient** (RR 1.90, 95% CI 1.88-1.93)* especially mental health services (4.56, 4.31-4.83)
- and **inpatient care** (general 1.67, 1.65-1.68, maternity 1.24, mental health 1.23, 1.15-1.31), compared to patients missing no GP appointments
- **Emergency department use was the same across all groups (** 1.00, 0.99-1.01)

*negative binomial regression modelling controlling for age, sex, SIMD and number of long-term conditions.

(Williamson et al Plos One 2021)

Hospital missingness

- Patients who had patterns of high missed GP appointments were **more likely** (RR 1.62, 95% CI 1.60-1.64)* to **miss hospital outpatient appointments**
- A **much higher risk** of non-attendance for **mental health services** (7.83, 7.35-8.35).
- Patients with high missed GP appointments were **more likely** (4.56, 4.31-4.81) to experience an **'irregular discharge' from inpatient care**
- No difference for ED 'left before care complete' between GP missed appointment category (1.02, 0.95-1.09)

*negative binomial regression modelling controlling for age, sex, SIMD and number of long-term conditions.

(Williamson et al Plos One 2021)

Relative risk of did not attend/irregular discharge/left without care completed

Zero
Low
Medium
High

Outpatient (SMR00) did not attend

Inpatient (SMR01) irregular discharge

Emergency department (ED) left without care completed

0.8 1 1.5 2 2.5 3 3.5 4 4.5 5 5.5 6

Rate ratios with 95% confidence intervals

(Williamson et al Plos One 2021)

Life course social context

Patients at higher risk of missingness are more likely to have

- an ACE recorded in their GP record (Williamson et al BJGP Open 2020)
- From education linked data:
  - reduced school attendance
  - higher levels of school exclusion
  - lower educational attainment (McQueenie et al BMC Medicine 2021)

Epidemiology key conclusions

- **Patients** at high risk of missingness are characterized by poor health, higher treatment burden, complex social circumstances and have higher premature mortality
- **General practice appointment scheduling** and context is important
- **Patterns of missingness persist across secondary care** outpatients and inpatient ‘irregular discharges’; patients are NOT seen in ED instead
- **Missingness is a strong risk marker for a poor outcome** so needs urgent attention from health service planners and practitioners

Current Realist Research

Dr Calum Lindsay, Dr David Baruffati, Prof. Geoff Wong, Prof Mhairi Mackenzie, Prof Sharon A. Simpson, Prof David E. Ellis, Michelle Major, Prof Kate O'Donnell, Prof Andrea E. Williamson

Acknowledgements: Elspeth Rae research administrator, Jack Brougham illustrator, research interview participants and Stakeholder Advisory Group members.

Research Questions

What do studies and key stakeholders say about the **causes** of missingness?

What do studies and key stakeholders propose might work to **address** missingness?

Methods

‘Realist approach’: Started with an initial programme theory, refined through three work-packages

1) **Realist Synthesis of Literature**
   - In-depth review of 197 documents
   - Developing narrative from flawed literature

2) **Qualitative Interviews**
   - 61 professionals and experts-by-experience of missingness
   - Sampling across relevant domains

3) **Stakeholder Advisory Group**
   - Consisting of 8 experts-by-experience and 8 professionals

Theoretical framework: drawing on theories of candidacy and fundamental causation

Problems with existing approaches

- **Defining the problem:** an issue for services, caused by patients, contributing to waste and inefficiency.
- **Exploring the problem:** little on causes; excluding some patient groups.
- **Fixing the problem:** Simplistic solutions, flawed measures, recruitment issues. Not *who* they impact and *how* – and who is left out.
- From a situational perspective → **a missingness lens.**

Overview of findings

Missingness is caused by:

- Interaction between service- and patient-side drivers, shaped by **wider structural context**
- **Overlapping** causes at different points in patient ‘journey’
- Issues that **endure** over time, but which **are amenable to change**

(Lindsay et al, BMC Medicine 2024)

“I haven’t missed very many NHS appointments, but that’s through *vast* amounts of effort. All these factors interplay and […] it’s surprising anyone ever gets outside the door because it’s all stacked against you.” (Sharon, Peer Support Worker, Inverclyde)

‘Is this for me/us?’

People don’t feel that their appointments or the service are **‘for them’**:

- **Don’t recognise a problem** or a need to attend
- Have **low expectations** around ability of appointment to solve their problem
- Are **anxious** or worried about what the appointment involves/might mean
- Attending might cause/worsen **shame, embarrassment or stigma**
- See themselves as **‘undeserving’** of healthcare

“The feelings ae inadequacy and ‘less than’ override everything else. Like, low self-esteem, low confidence, low mood. […] When you're one of the least deserving… or you see yourself as one of the least deserving people, when somebody reaches their haund… […] because you believe already that you don’t deserve it, you arenae gonnae take the haund…”

(Jim, Glasgow)

Past experiences of seeking help

What services have **offered people** in the past/how they have **treated people**:

- **Disagreement** about:
  - Causes of/solutions to a health problem
- **Communication**:
  - Language, literacy, mental health, cognitive issues, confidence
  - No space, time or help to communicate

Result:

- People offered things that don't fit with their needs/circumstances; reduced trust in healthcare system

"People who've got no experience of systems working for them in terms of economic systems and jobs... Why again would they have trust in organisational things that are set up mostly around people who have organised lives and jobs?" (Lesley, Consultant Psychiatrist, Glasgow)

Rules for access

‘Rules’ for using the service may not match people’s resources or circumstances:

- **‘Gatekeeping’ staff and systems:** increasingly complex; negative first encounters
- **Delays and inconvenient timings:** long waits, and unsuitable opening times and appointment times
- **Appointment inflexibility:** how, when, who, where, how long; no flexibility for ‘wrong presentations’
- **Administrative errors:** mistakes, miscommunications and inaccessible systems
- **‘Conflict’ dynamic:** constant requirement for strong advocacy

“I get blamed for being aggressive when I don’t know what assertive means.” (Paul, Glasgow)

“There's a constant dynamic of conflict […] and this is a theme you'll find from anybody you speak to, who has a child or an adult with complex health needs, a constant fight. And some people; they get exhausted, and they give up, and I can't blame them.” (Jodie, Glasgow)

Competing demands

May have greater demands/fewer resources:

- **Treatment burden:** lots of appointments and fewer resources to manage them; poorly coordinated by services
- **Work and money**: inflexible work, benefits appointments, losing money/ risking job security to attend
- **Caring responsibilities:** for children/other family members
- **Shifting priorities and recurring crises:** unmet basic needs, urgent demands and precarity/exposure

"It's all very much about the now, where you're going next. How you're going to make a living. […] Is it 'go to the appointment', or 'I've just been offered this job, which is going to give me a couple of hundred quid in the pocket, which is going to make a difference."
(Naomi, Gypsy Traveller, Brighton)

Getting to an appointment

Getting to an appointment can be difficult because of:

- **Travel and transport:** costs, time, restricted options and ‘difficult journeys’
- **Symptoms:** feeling too unwell to travel, physically or mentally
- **Safety:** feeling unsafe in public, in waiting rooms or certain locations around healthcare settings
- **Forgetting:** when, what, and where – ‘wayfinding’

If every journey is hard *lots* of journeys are harder

“I describe my coming to Scotland as homeless, pregnant and alone. [...] They were giving me a 30 pounds stipend. [...] I needed to check into the hospital every single day to get myself checked. [...] Most times, really, I missed the appointments, because I just couldn’t afford to get myself there. I had to choose between food and go hospital. [...] If I’d felt my baby moving that day or she’s kicked about, I would say, well, at least today I felt the movement [...] If anything happened, I wouldn’t, you know, stop blaming myself.” (Billie, Glasgow)

Mistrust, stigma, trauma, discrimination

Mistreatment in care can lead to mistrust/threat:

- **Early (and ongoing) experiences:** influence future relationships (attachment, trauma)
- **Stigma, discrimination and hostility:** experienced, internalised or anticipated
- **Service mistreatment:** feeling blamed, punished, neglected, unworthy and unsafe
- **Misunderstanding of 'missingness':** seeing as patient 'choice'/flaw; punitive response
- **Prioritisation of 'easier patients':** not evoking sympathy; invisible; behaviours seen as 'choice'

"The NHS attitude with me was, because I was a drug addict.... a black, male, homeless drug addict, there was no point in the NHS spending any money on my rehabilitation. Because I was just gonna go back to doing drugs again, the usual," (Jason, Salford)

Applying a missingness lens

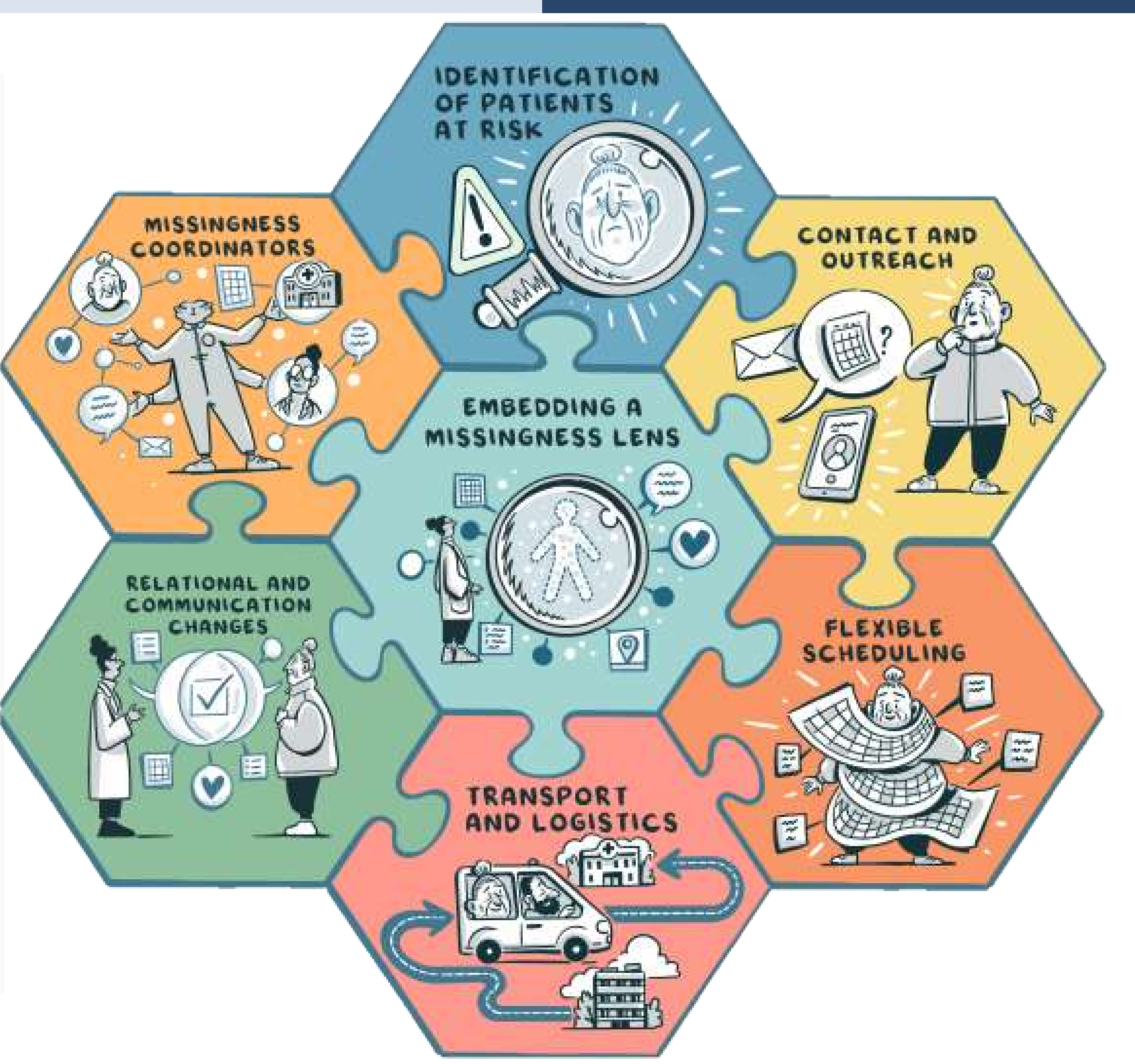
The 'situational' model		A missingness lens
Patient 'responsibilisation'	→	**Services** commit to identifying/addressing barriers
Shallow, monocausal perspective	→	**Complex causality** for individuals, in contexts
Standardised approach to whole population	→	**Proportionate universalism** in prioritising resources.
Technical solutions	→	**Relational responses** - empathy, relationships, communication.
Practical and logistical approaches	→	Oriented around **safety -** structural, cultural, psychological
Biomedical models of healthcare	→	Incorporating SDH, poverty, marginalisation, broader view of health
Single-service, resourceless approaches	→	**Collaborative approaches**, incentivised and **resourced**
Hierarchical, service-oriented solutions	→	**Patient agency - choice, empowerment and collaboration**

Our Interventions

Designed as a package of reinforcing activities, each building and depending on the others.

Implemented on a needs-led, patient-centred basis, oriented around **embedding a missingness lens.**

There are broader structural/policy issues that need to be tackled but these are beyond our scope.



Wayfinding, meeting broader needs, advocacy, coordination, *doing whatever is needed* among these interventions.

Attention to causes, solutions and local dynamics: staff development and support to create a positive approach to missingness; feedback, monitoring and accountability

Using multiple sources of knowledge; identifying barriers, building relationships, assessing and recording key information. **Building a picture** – individual + collective.

Choice/continuity of staff; addressing comms needs and power dynamics; advocacy work.

Contact before/after appts – reminders; orientation; explore immediate barriers; offers of support; check-ins; offers of care.

A stepped, needs-led approach: Tickets/reimbursement -> taxis -> accompaniment.

Prioritising 'missing' patients for different/flexible forms of access: choice of when, where, how; longer appts/opening hours;

IDENTIFICATION OF PATIENTS AT RISK

MISSINGNESS COORDINATORS

CONTACT AND OUTREACH

EMBEDDING A MISSINGNESS LENS

RELATIONAL AND COMMUNICATION CHANGES

FLEXIBLE SCHEDULING

TRANSPORT AND LOGISTICS

Conclusions and next steps

- Missingness a strong risk factor for negative outcomes BUT has clear causes that can be addressed.
- Requires a perspective shift towards a ‘missingness’ lens, with a suite of interventions guided by these strong principles.
- **What’s next?** Finalising intervention design; opportunities for future piloting and development; dissemination and impact.

Thank you!

Addressing missingness already? email our research team
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Direct email address for Andrea Williamson
andrea.williamson@glasgow.ac.uk
Further information about the research (papers, presentations, what we are doing now) can be found here on the Missingness Interventions, University of Glasgow webpage