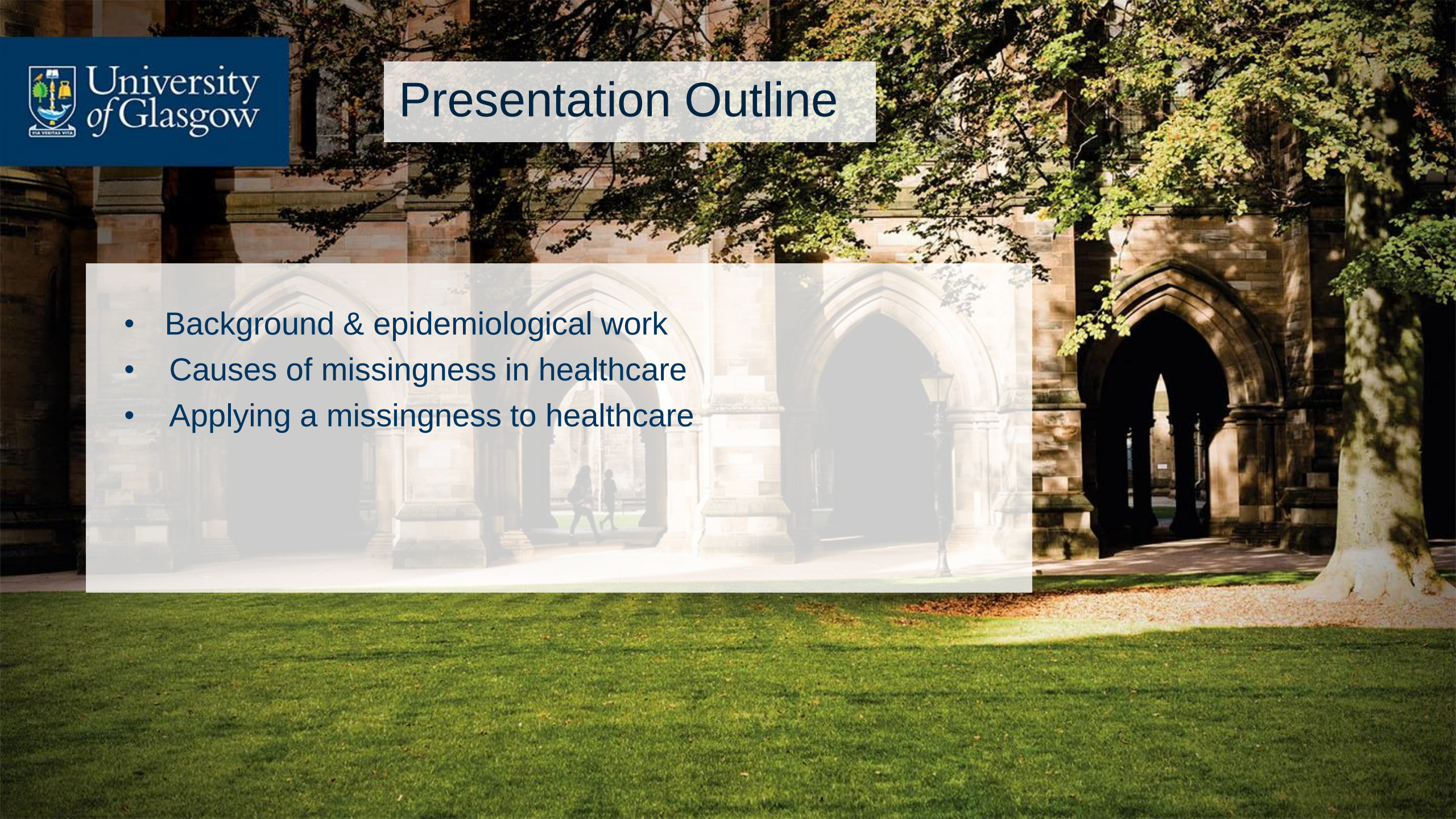
Missingness in health care- importance, causes and solutions

Prof Andrea Williamson on behalf of the missingness research team, VHS, March 2025



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Presentation Outline

- Background & epidemiological work
- Causes of missingness in healthcare
- Applying a missingness to healthcare

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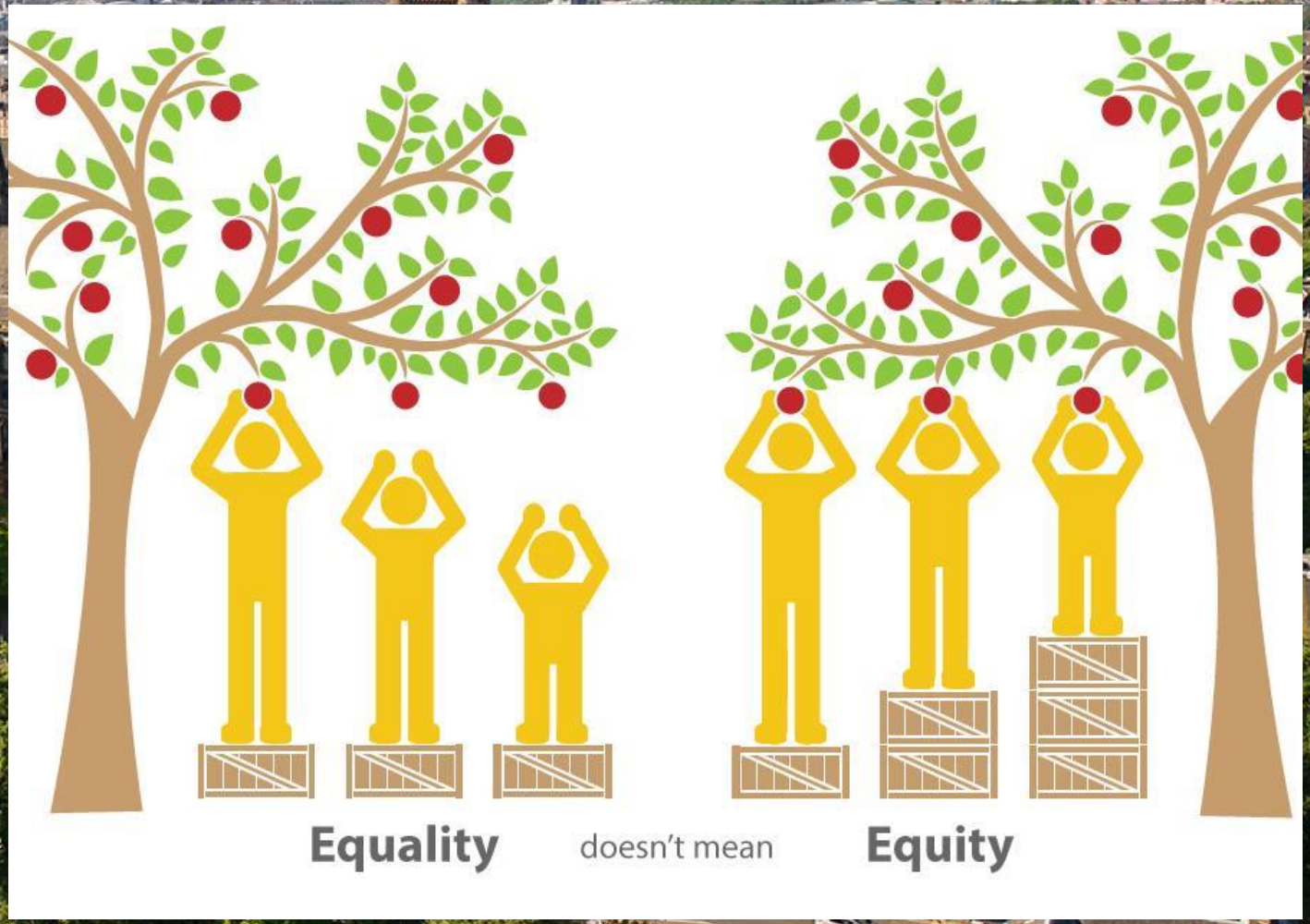
Context &influences

GPs at the Deep End

Acknowledgement

We acknowledge the survivorship of the people who are in Inclusion Health groups and who we meet and represent in our work. They continue to be an inspiration to us through their resilience and strength in the face of adversity.

The importance of equity 1

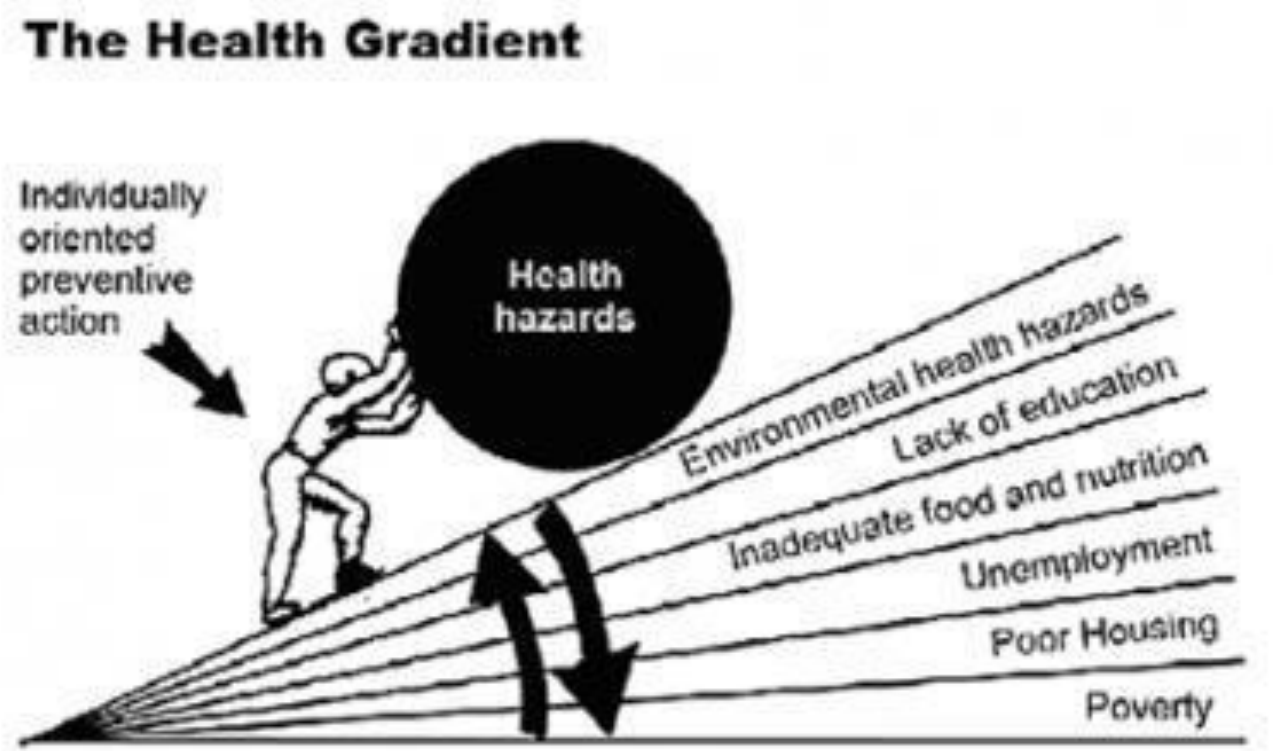


The importance of equity 2

INEQUALITY AND ACCESS

Those with least in society struggle more in accessing healthcare than those who are better off.

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

Missed appointments results

136 Scottish representative GP practices

550 083 patient records

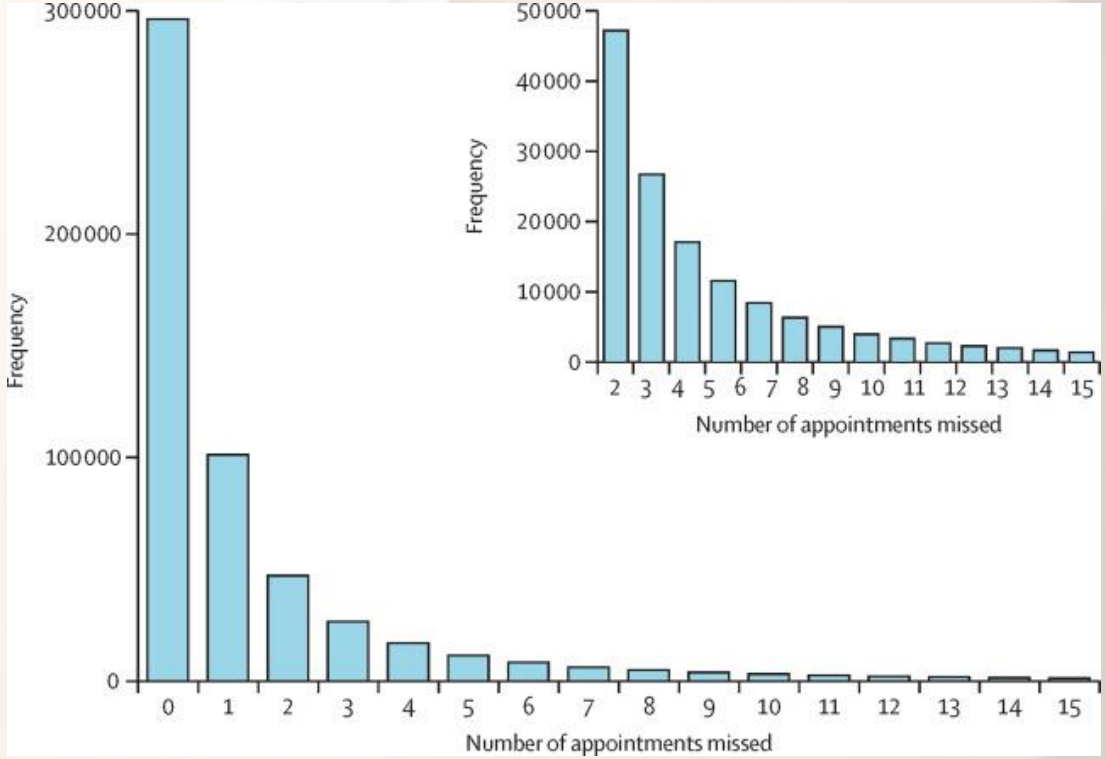
9 177 054 consultations

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

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

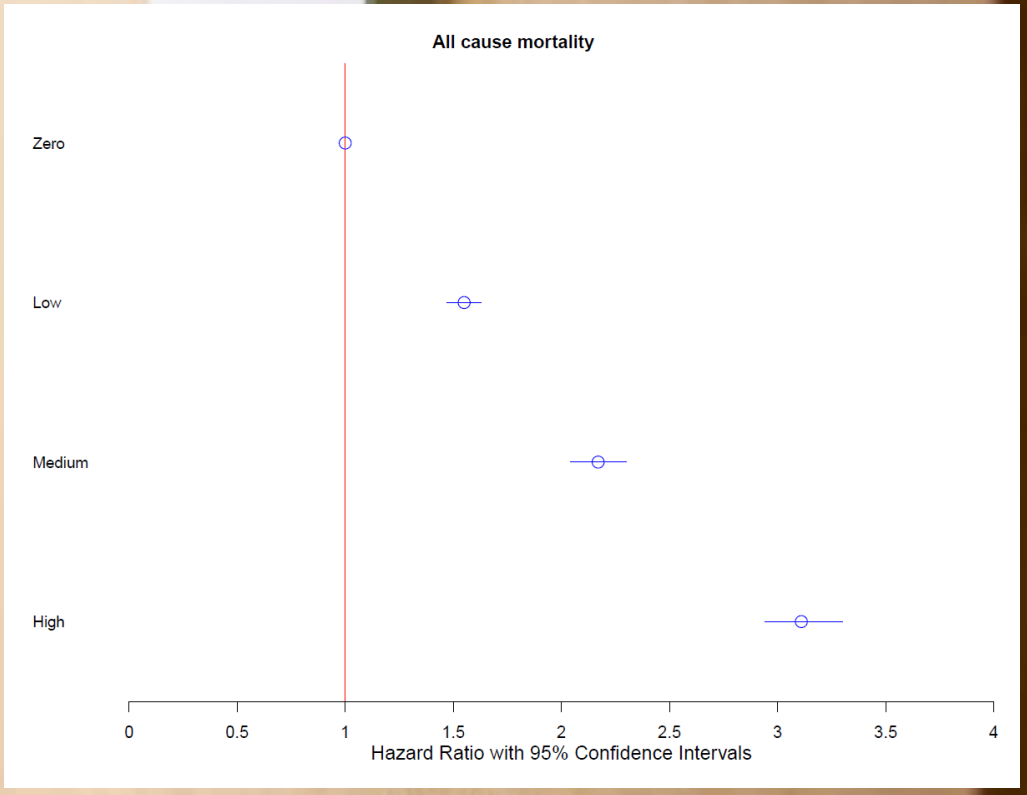
19·0% (104,461) missed more than two appointments

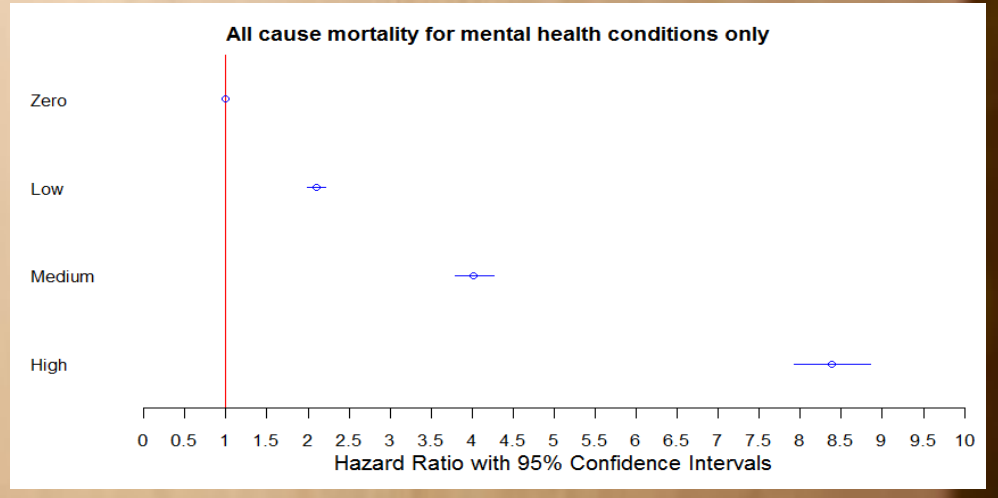
(Ellis, McQueenie et al Lancet Public Health 2017)



Epidemiology

- **Patients** at high risk of missingness are characterized by poor health, higher treatment burden, complex social circumstances and have higher premature mortality (McQueenie et al BMC Medicine, 2019, Williamson et al Plos One 2021, Williamson et al BJGP Open 2020, McQueenie et al BMC Medicine 2021)
- **General practice appointment scheduling** and context is important (Ellis, McQueenie et al Lancet Public Health 2017)
- **Patterns of missingness persist across secondary care** outpatients and inpatient 'irregular discharges'; patients are NOT seen in ED instead (Williamson et al Plos One 2021)
- **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

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Methods

I. Realist literature review (254 papers)
II. Interviews (61 participants)
III. Stakeholder Advisory Group (16 participants)

Broad range of clinical, social and inclusion health backgrounds

Missingness caused by interaction between overlapping service- and patient-side drivers, shaped by wider structural context, enduring over time.

"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)

What causes missingness? (Lindsay et al 2024)

- Patients not feeling the service is **‘for’ them:** necessary, helpful, appropriate, safe.
- **Past experiences**: mistreatment, poor communication, power imbalances, offers do not help/‘fit.’
- **Getting there:** travel, transport, space and place.

“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)

What causes missingness(2)? (Lindsay et al 2024)

- **Access rules:** difficult to understand/navigate; gatekeeping; delay; inflexibility; errors/mistakes.
- **Competing demands/limited resources:** appointments, work/money, relationships, survival.
- **Mistrust/distrust:** stigma, trauma, discrimination, mistreatment, misunderstanding, “easier” patients.

“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)

Intervention Development Process

- Synthesising literature, interview and StAG findings.
- Extended stakeholder involvement for insight, contextual relevance and equity.

“Changing relationships, displacing existing activities and redistributing and transforming resources” (Wight et al 2016)

The 6SQuID Method

1. Define and understand the problem: from the classical model to the missingness lens.
2. Identify factors that can and should be changed.

¾. Identify how to bring about change – the “change mechanism” - and how to deliver it in context.

Redefining the problem – a missingness lens

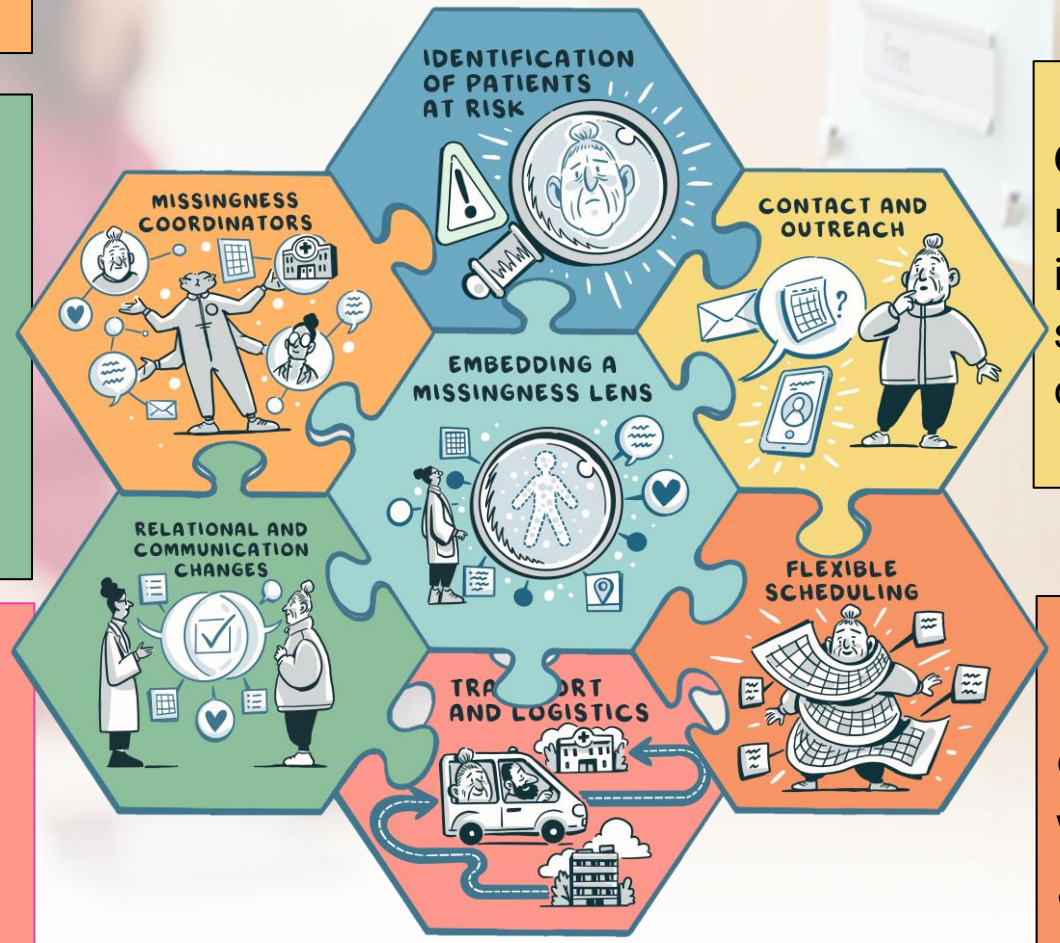
The 'situational' model	A missingness lens
Patient 'responsibilisation'	**Services** committed, resourced, incentivised to identify and address barriers
Shallow, monocausal perspective	**Complex causality** for individuals, in contexts (tailoring)
Technical, practical, logistical	**Safety -** structural, cultural, relational, psychological
Standardised, service-oriented	Proportionate universalism and positive selectivism
Biomedical models of healthcare	**Condition Competency,** addressing SDOH, poverty, & marginalisation
Hierarchical, service-oriented solutions	Person-centred approaches

Coordination: bridging work; address SDOH and patient priorities, advocacy and promoting system change. Open-ended, flexible, relational.

Resourcing a change in perspectives, practices, systems; staff development and support; build in localised perspectives; means for monitoring and accountability

Identifying and tracking local patterns and trends.
Exploring barriers while building relationships.
Building a picture – individual + collective.

Person-centred, trauma-informed practices.
Choice/continuity of staff; addressing comms needs and power dynamics; advocacy work.



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

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

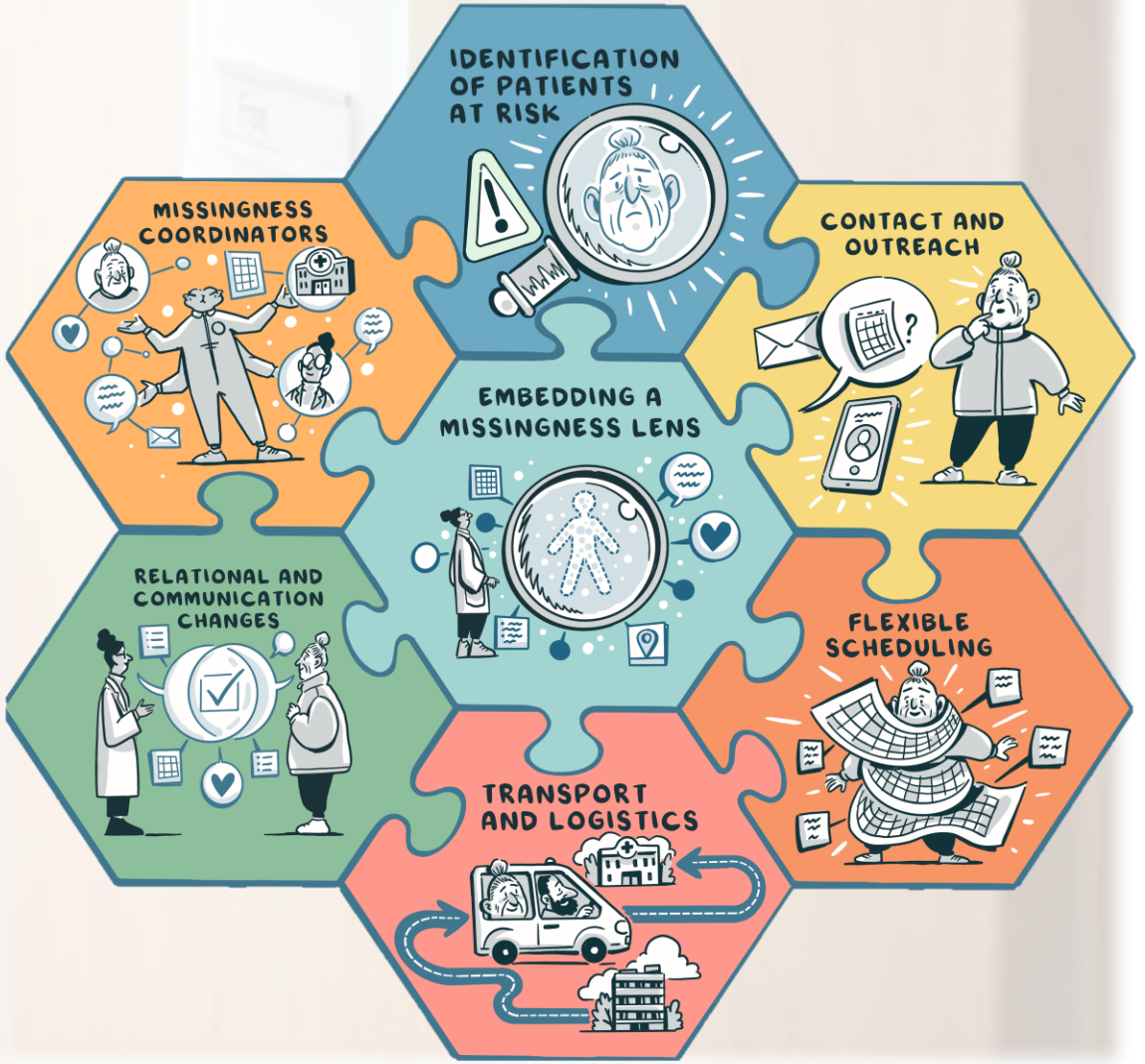
Prioritising for flexible forms of access: choice of when, where, how; longer appts/opening hours;

Missingness Interventions (unpublished)

Designed as a ‘suite’ of activities – “a ‘recyclable’ core set of processes that can be judiciously applied.” (Pearson et al 2015)

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

A systems perspective – creating conditions to disrupt the system that creates and sustains missingness.



Conclusions

- 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.
- Issues at structural/policy ‘level’ need to be tackled but these are beyond our scope.
- Provides a purposeful organising framework for Inclusion Health and mainstream services.

Thank you!

Addressing missingness already? email our research team
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Further information about the research (papers, presentations, what we are doing now) can be found here on the Missingness Interventions, University of Glasgow webpage

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