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Scotland's Vital Health Sector

VHS Annual Conference 2024

20 years vhs voluntary health scotland

Missingness in healthcare

VHS seminar October 2024

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on behalf of the Missingness research team

Outline

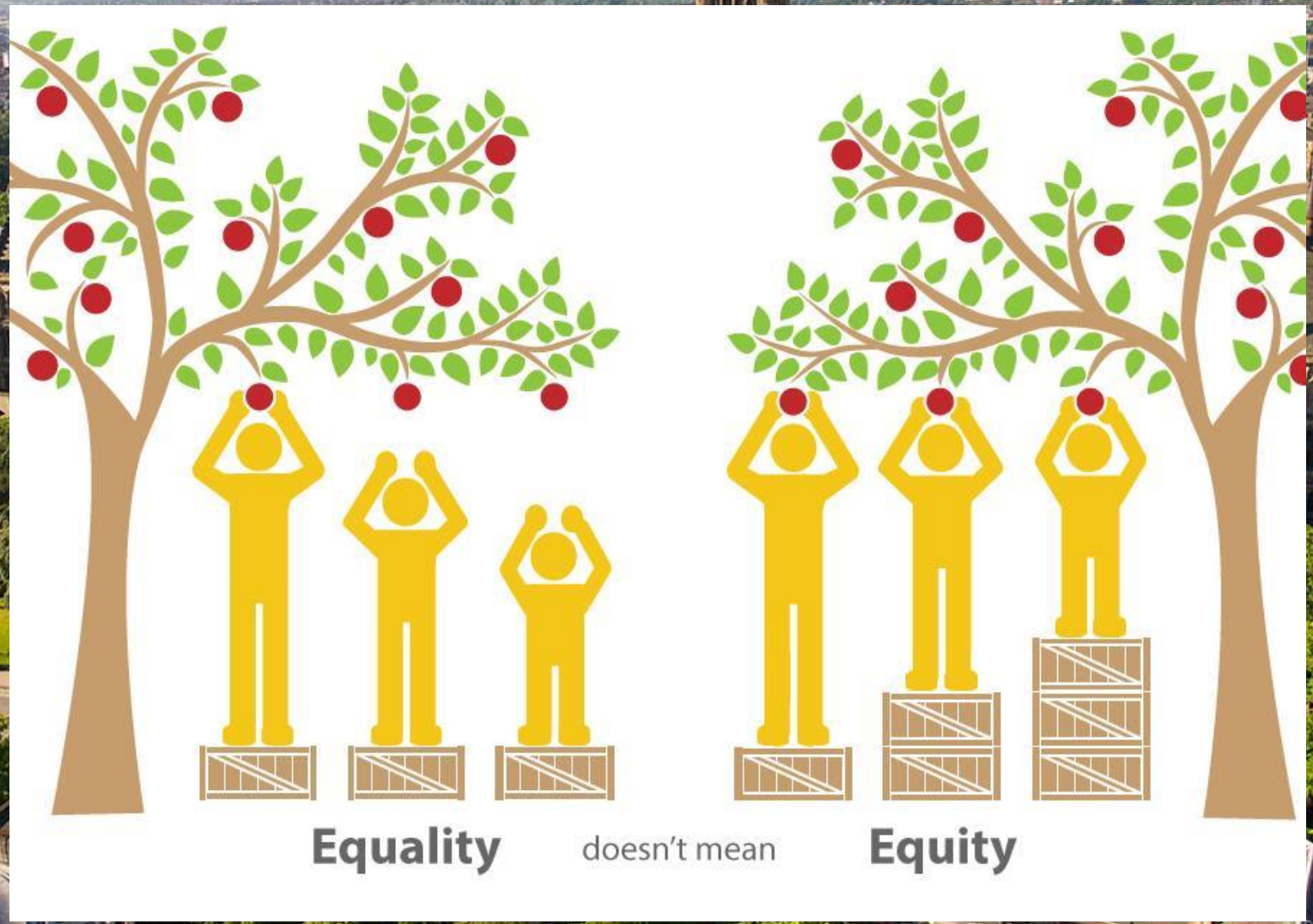
- Introduction
- Multiple missed appointments epidemiology
- Missingness in health care
- What can be done?


University of Glasgow
Glasgow
NHS
Greater Glasgow and Clyde
Hunter Street Homeless Services
No Smoking
In the Grounds or Buildings of 55 Hunter Street
SOUTH ADRS
GPs at the Deep End

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.

Importance of equity 1



Importance of equity 2

INEQUALITY AND ACCESS

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

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

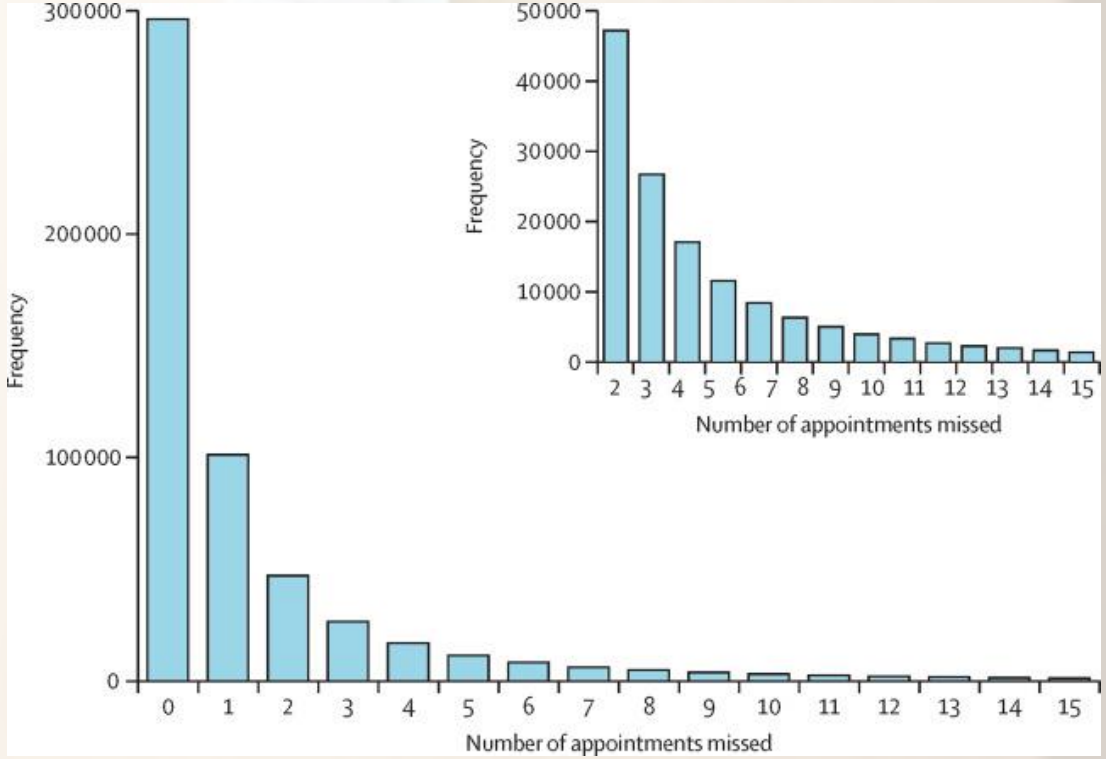
9 177 054 consultations

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

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

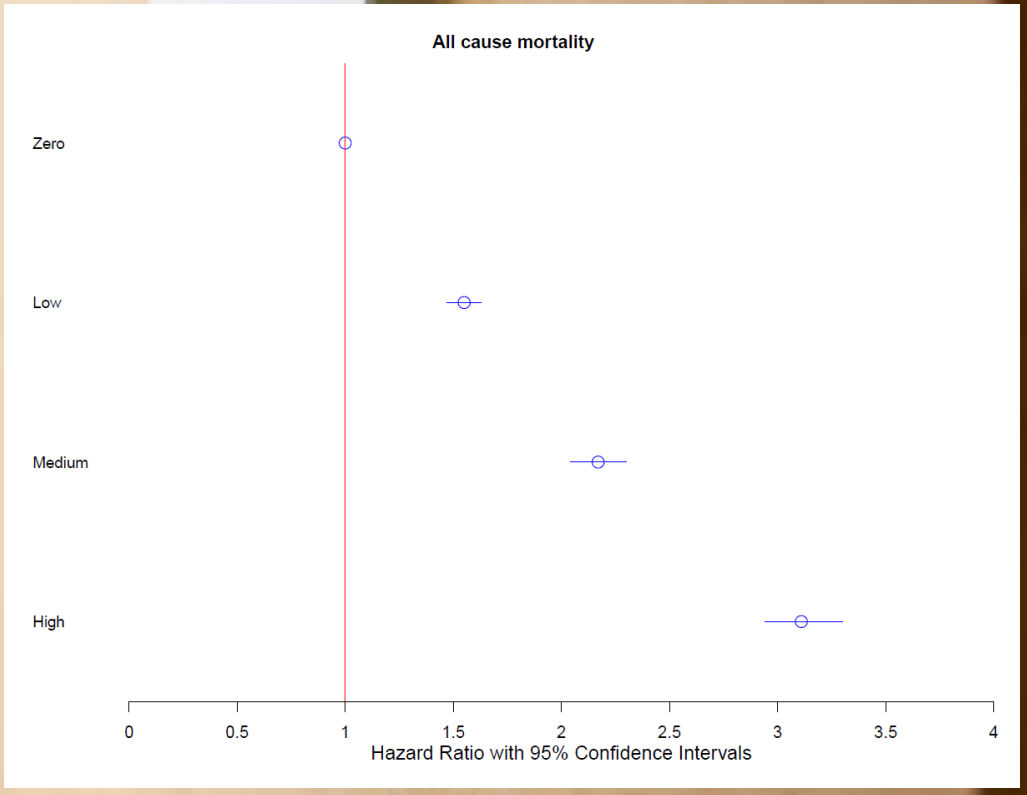
19·0% (104,461) missed more than two appointments

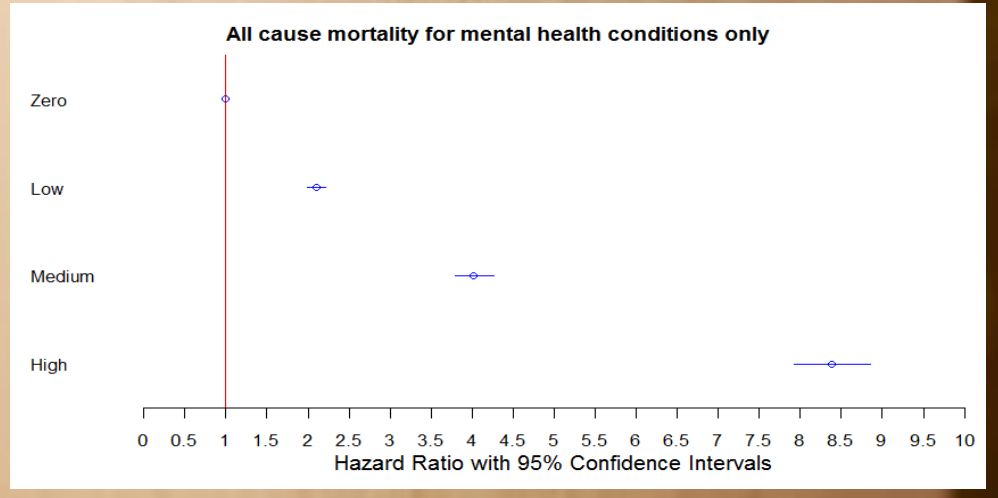
(Ellis, McQueenie et al Lancet Public Health 2017)



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

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

Research gaps and our focus

- **Weaknesses of 'missed appointments' literature:** conflation of single/multiple missed appointments; unhelpful framing of issue
- **Research gap:** poor understanding of *why* people miss multiple appointments and what can be done to help
- **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 9 experts-by-experience and 9 professionals

Theoretical framework: drawing on theories of candidacy and fundamental causation

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, 2023)

“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)

‘Taking a missingness lens’

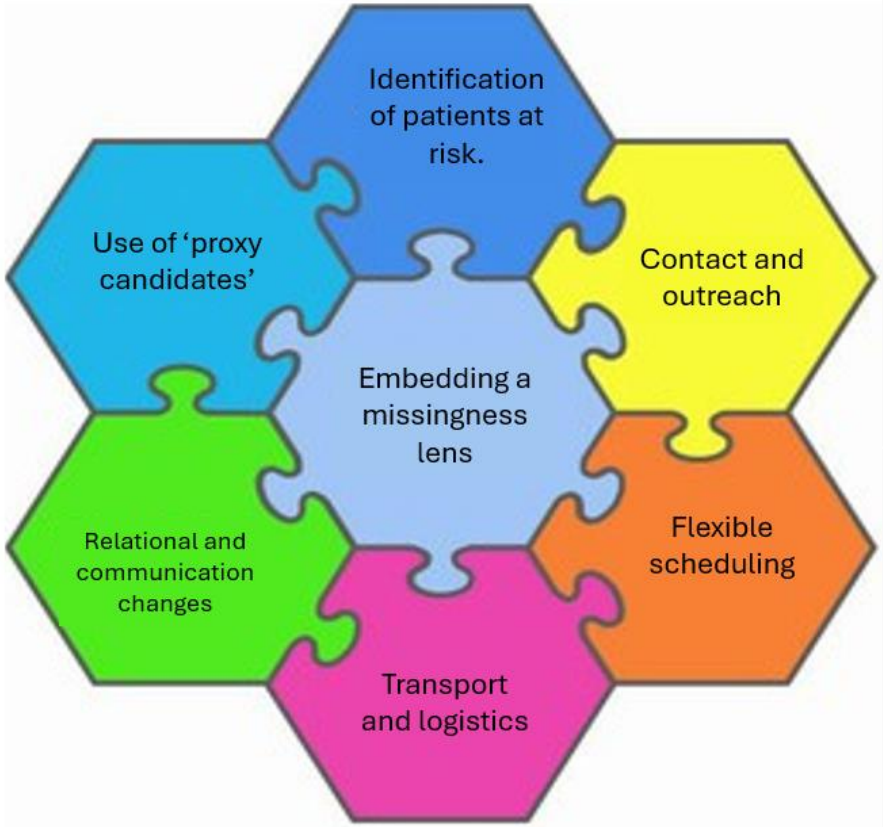
The “situational” paradigm	**A missingness lens**
Patient responsibilisation	Service commitment to identify and address barriers to care
Shallow, monocausal perspective	Complex causality for individual patients, and in wider service and community contexts
Intervening across patient population	Proportionate universalism: prioritising resources for those who need them most
Technical solutions	Solutions rooted in empathy, relationships and communication
Practical and logistical approaches	A structurally, culturally and psychologically informed approach, oriented around ideas of safety
Medical models of healthcare	A view incorporating and addressing SDH, poverty, marginalisation, and exclusion, using a broader view of health and wellbeing
Single-service, resourceless approaches	Collaboration between and across services, with incentives and resources appropriate to the task
Hierarchical, service-oriented solutions	Patient agency, choice, empowerment and collaboration

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

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

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

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



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

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

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

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 strong principles.
- **What’s next?** Finalising intervention design; opportunities for future piloting and development; dissemination and impact.

Thank you!

Please contact us at missingness@glasgow.ac.uk with any further questions or comments, and see https://www.gla.ac.uk/schools/healthwellbeing/research/generalpractice/research/missingnessinterventions/ for further details.

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