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Missingness in healthcare, importance, causes and solutions

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Andrea Williamson, Professor of General Practice & Inclusion Health, on behalf of the missingness research team

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Presentation Outline

- Introduction and context
- Background epidemiological work
- Causes of missingness in healthcare
- Addressing missingness in healthcare

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Context & influences

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.

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

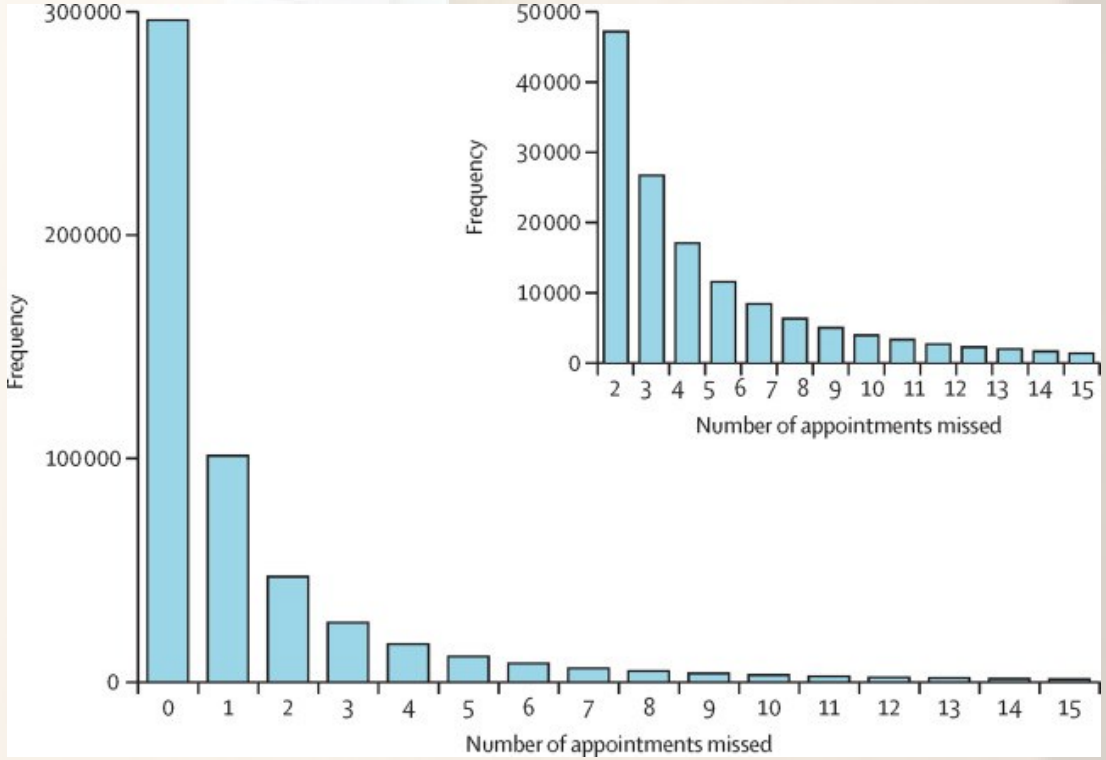
9 177 054 consultations

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

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

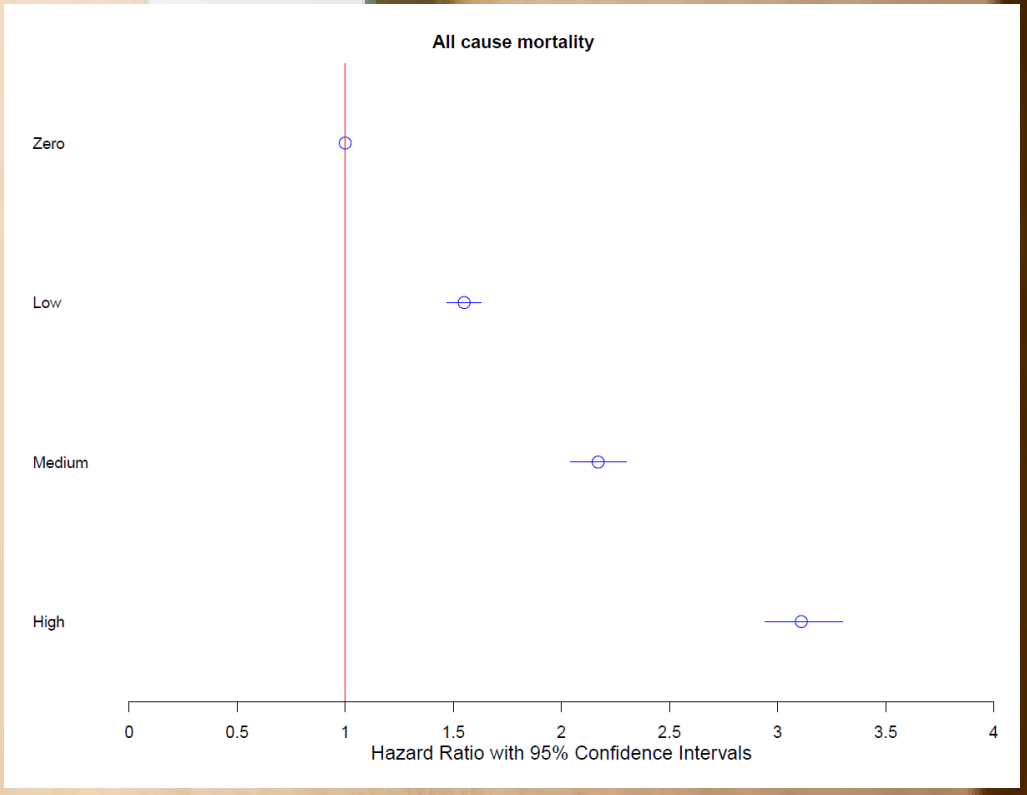
19·0% (104,461) missed more than two appointments

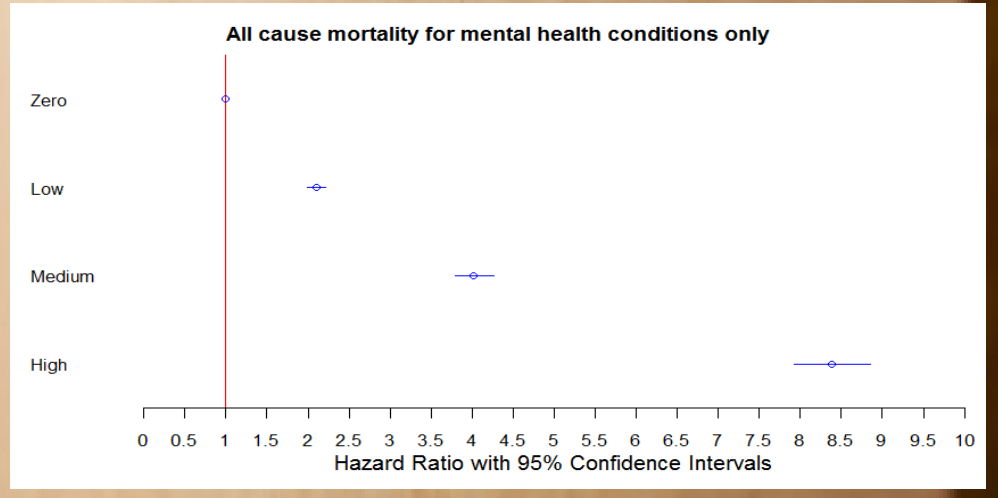
(Ellis, McQueenie et al Lancet Public Health 2017)



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

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

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.**

What causes missingness?

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Methods:

I. Realist literature review (197 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)

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.

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
missingness@glasgow.ac.uk
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

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