

## 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

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Researcher: Ross McQueenie

Collaborator: Mike Fleming

Trusted Third Party: Dave Kelly Albasoft

Participating GP practices

Colleagues at Scot Gov and eDRIS



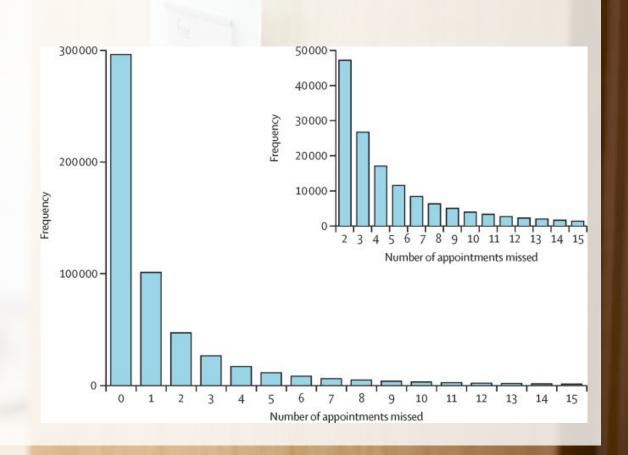
### Missed appointments results

136 Scottish representative GP practices550 083 patient records9 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

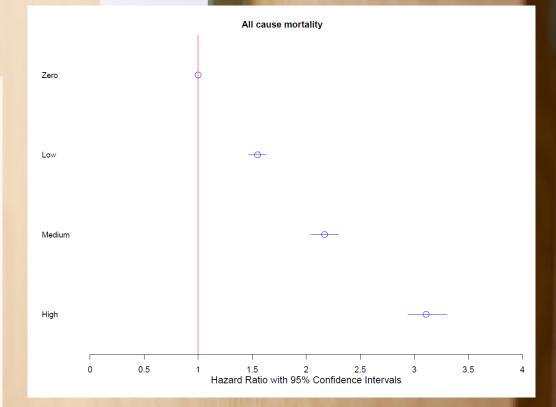
(Ellis, McQueenie et al Lancet Public Health 2017)

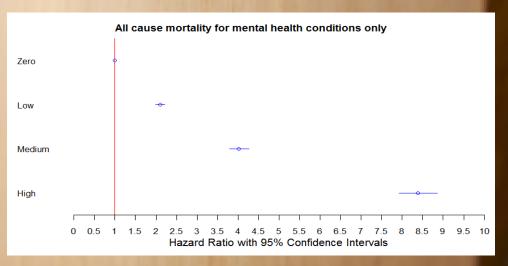




## **Epidemiology**

- 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









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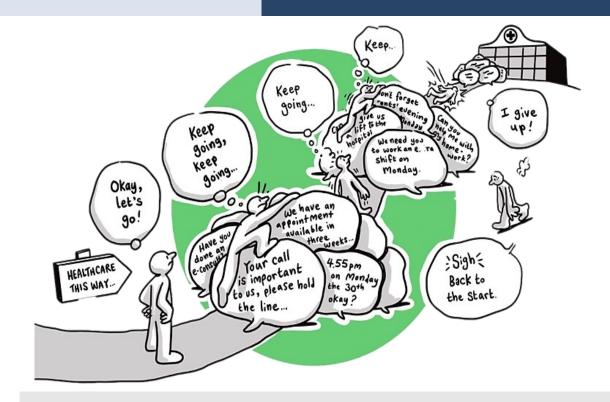
## Methods



- 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 patientside 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..."

## 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**



#### Realist principles

- 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

- Define and understand the problem: from a "one size fits all" model to a 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'	<b>Services</b> 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

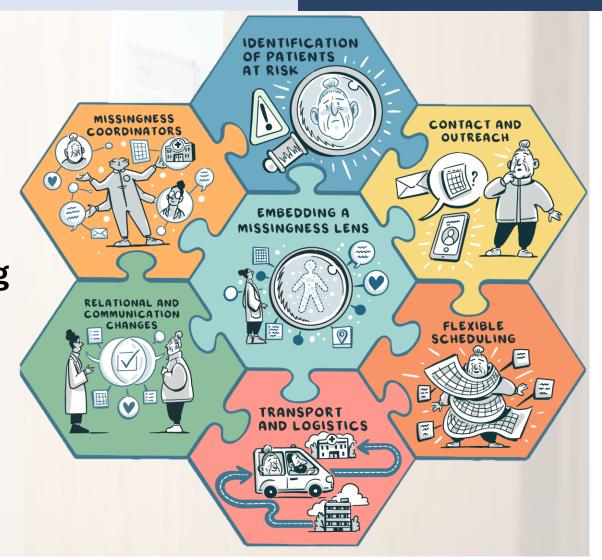
## Missingness Interventions (unpublished)



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, patientcentred basis, oriented around **embedding a missingness lens.** 

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



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

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, traumainformed practices. Choice/continuity of staff; addressing comms needs and power dynamics; advocacy work. MISSINGNESS
COORDINATORS
COORDINATORS

EMBEDDING A
MISSINGNESS LENS

RELATIONAL AND
COMMUNICATION
CHANGES

TRANSPORT

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 tailored forms of access: choice of how, when, who, where; longer appts/opening hours; allowances/accommodations.

## Conclusions



- Missingness is 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.
- 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 <a href="here">here</a> on the Missingness Interventions, University of Glasgow webpage







