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Missed but not forgotten: Applying a missingness lens to healthcare
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Disclosures

The team have no CoI or links to pharmaceutical companies.

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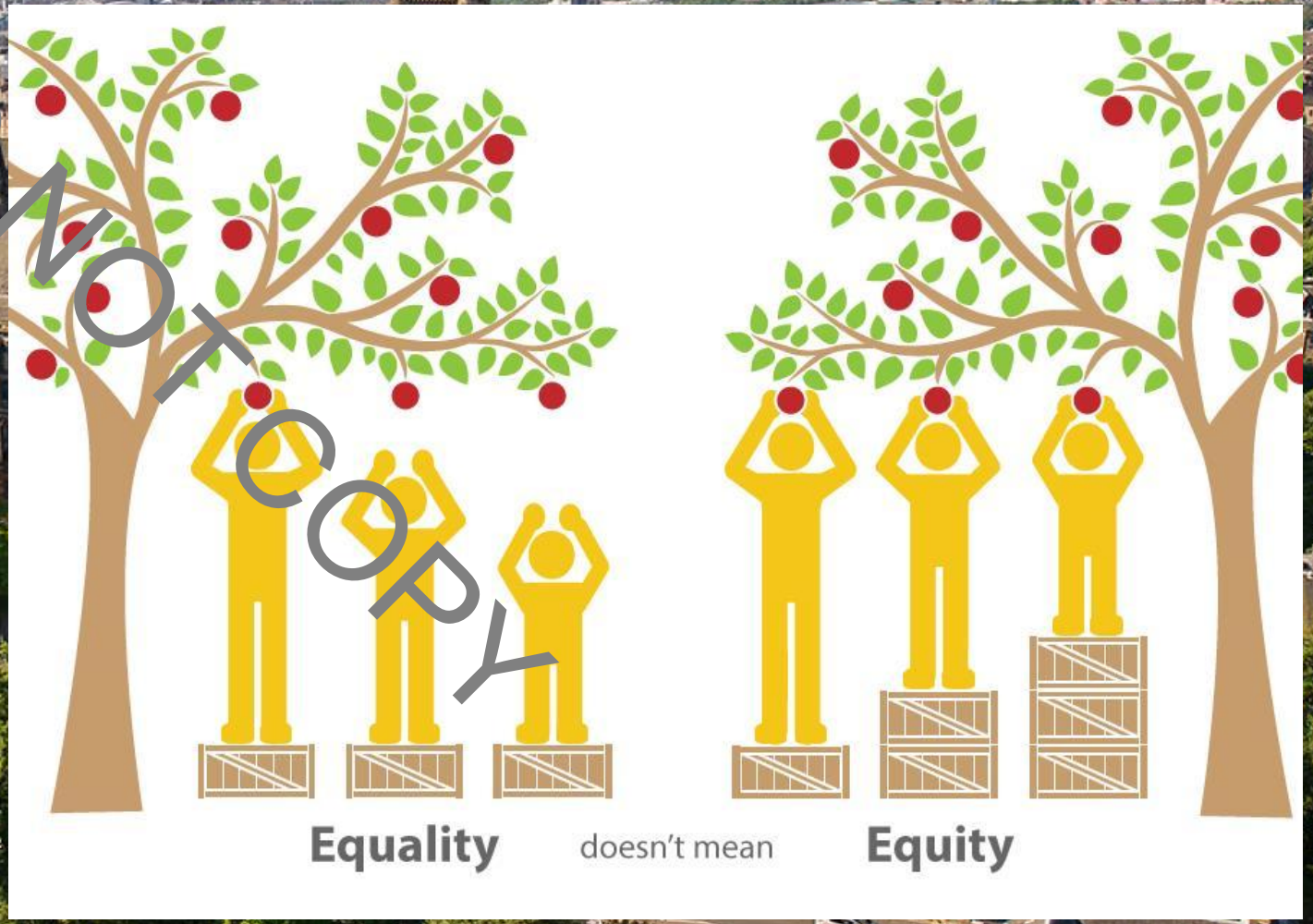
Presentation Outline

- Epidemiology of multiple missed appointments
- Causes of missingness
- Applying a missingness lens & interventions

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



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

PI: Andrea E Williamson
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

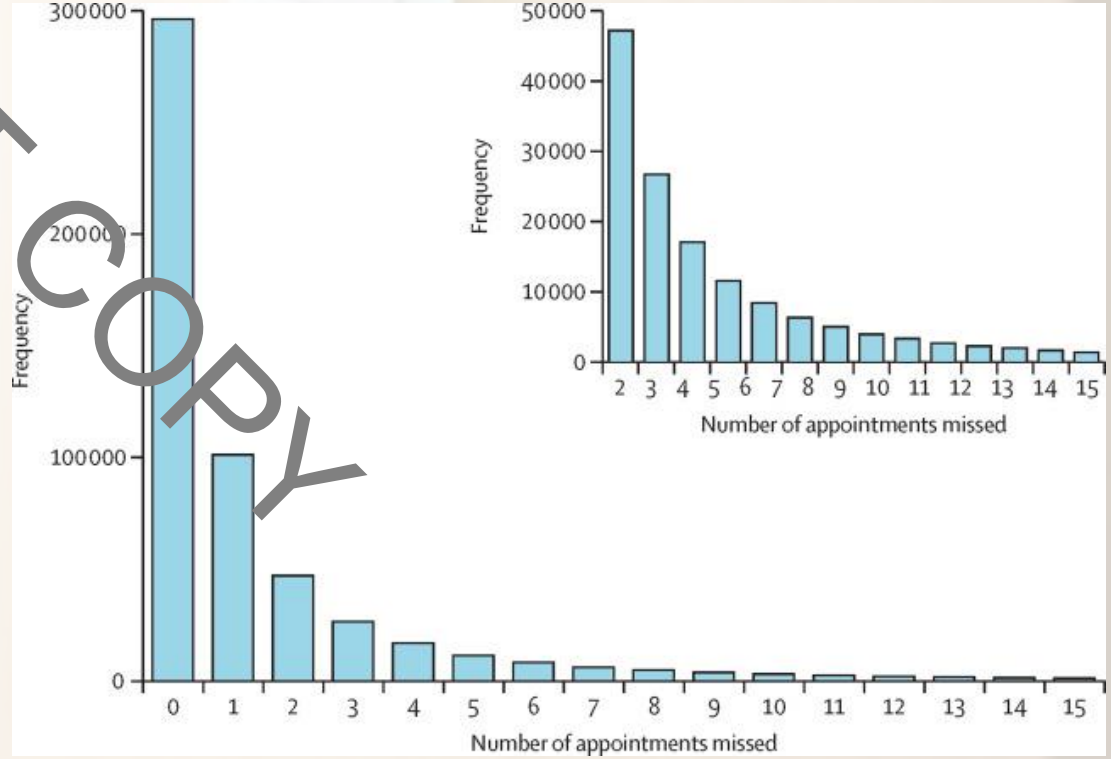
9 177 054 consultations

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

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

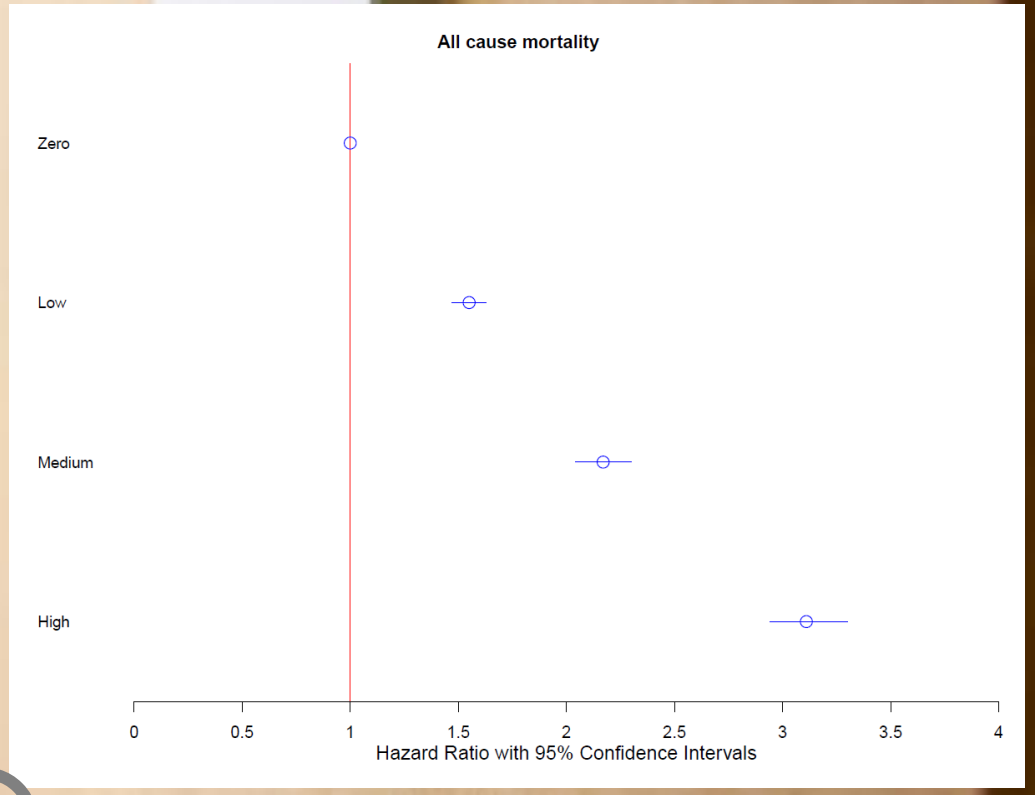
19·0% (104,461) missed more than two appointments

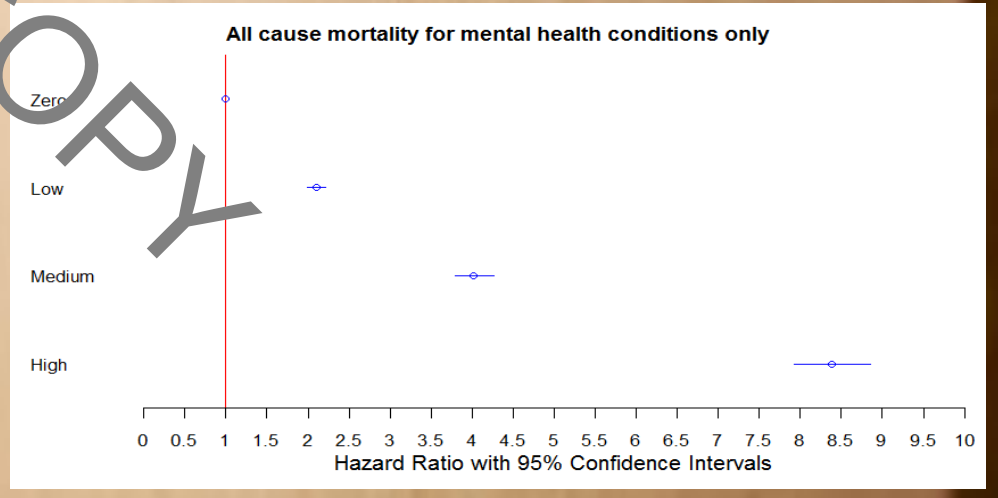
(Ellis, McQueenie et al Lancet Public Health 2017)



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)
- **<u>Missingness is a strong risk marker for a poor outcome</u>** so needs urgent attention from health service planners and practitioners





Current Realist Research

Dr Calum Lindsay, Dr David Barufati, 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

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

1. 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

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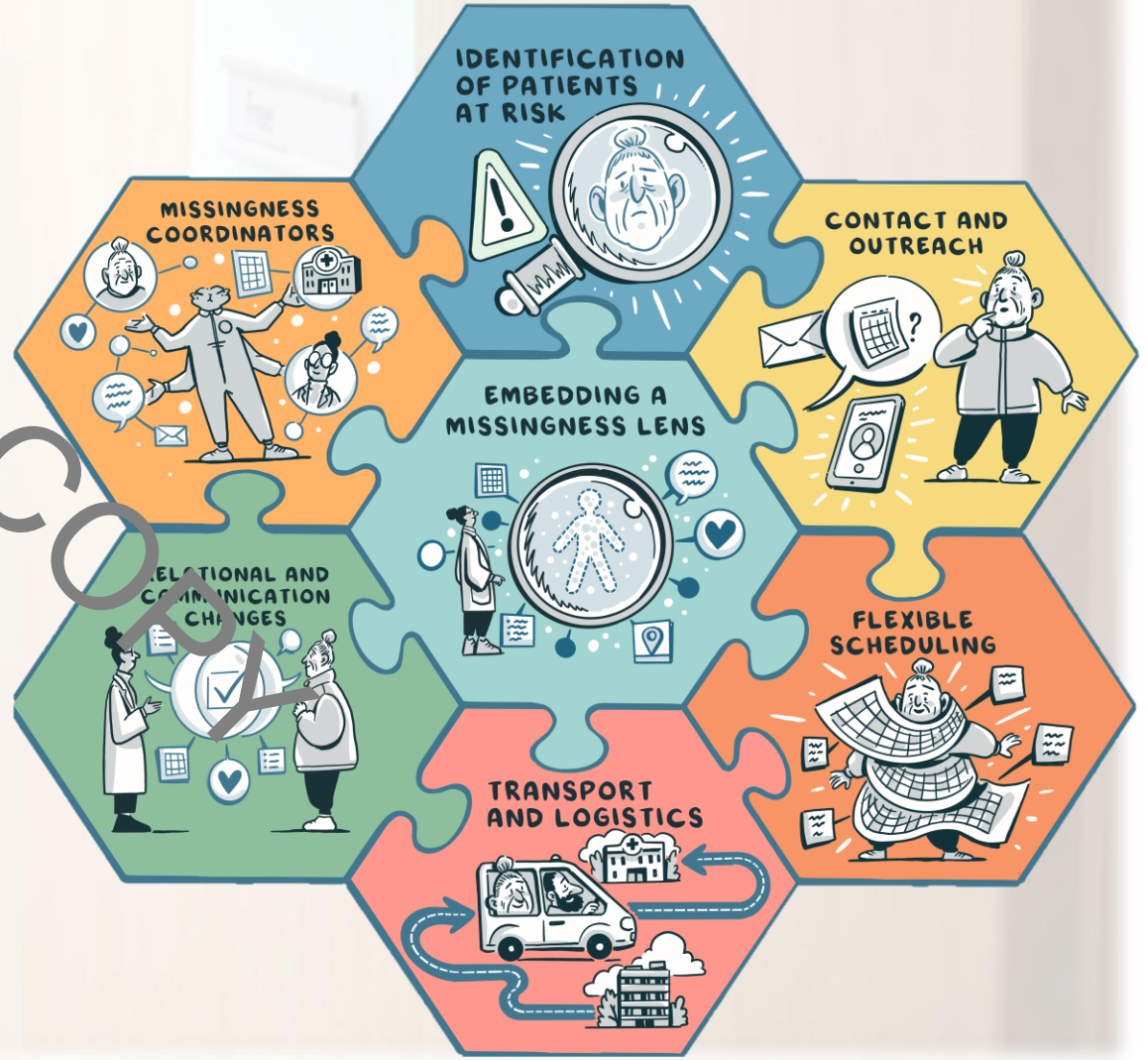
The 'situational' model	A missingness lens
Patient 'responsibilisation' →	**Services** committed, resourced, incentivised to identify and address barriers
Shallow, monocausal perspective →	**Complex causality** for individuals, in contexts (tailoring)
Technical, practical, logistical →	**Safety -** structural, 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

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.



Embedding a missingness lens

- Perspective change at all levels of NHS organisation & delivery.
- Matching perspective change with targeted resources (money, time, staff capacity…).
- localised plans for systems change – monitoring, evaluation, quality improvement with accountability.
- Training/awareness-raising for all NHS staff and on related topics.
- Ongoing staff support and environments to support new practice.

Identification

- Data systems to record attendance, identify/profile ‘missing’ patients, monitor trends.
- Guided by staff knowledge, wider ‘missingness’ signals, community orgs intelligence.
- Contact people to explore causes/circumstances, make plans.
- Relational approach – empathetic, collaborative, person-centred.
- ‘Patient Individual Needs’ document – foundation of consistency& accountability.

“what can we do to get you here? What’s going to make the difference?”

“Look at their whole lives really holistically”

“There should be a red flag flashing. […] Ravens flying above.” (EBE)

“Actually find out the reasons.”

Relationships and Communication

- Recentring relational care: trust, consistency, continuity, safety over time.
- Staff development on **relational care**, TIP, stigma, communication needs.
- **Trust** in a **consistent response** that meets patients' needs.
- **Continuity** (of clinician, approach, treatment, care).
- **Safety:** patient-centred approaches, address power imbalances.
- Avoid stigma, coercion, manipulation.

"professionals they can trust and build a relationship with [are] pivotal."

"It's all that relational, communication stuff, all of it."

"make them feel welcome."

"using that trauma-informed approach "

"know what language they speak"

"choice is vital."

‘Missingness Coordinators’

- Carry out key missingness tasks with patients.
- Person-centred, collaborative, flexible, open-ended support.
- “Bridging”, “brokering”, “mediating”, creating “safe passage”– build patient resources.
- Addressing needs beyond healthcare.
- Embedded; able to influence service change.

A holistic approach support worker, a jack of all trades.

“speak to that person about what they want and make it happen”

“[A] specialist worker who’s just focused on missingness”

Take them by the hand if necessary, find out what issues they’re struggling with, and then try and support them through.”

“have an understanding of the individual and share that into health.”

Flexibility

- **Prioritising** 'missing' patients for flexible, **tailored forms** of access.
- Agreement on **how** and **whether** appointments are made (e.g drop-ins or open access).
- **when** appointments are, and for **how long**.
- **who** they see, and **where** they are seen (named GP, home visits, outreach, telehealth).
- **Allowances and accommodations** for 'non-standard presentations' avoiding punishment.

"13 minute appointments really wasn't long enough"

"come in and we'll make space for you"

"flexibility around time"

"flexible drop-in appointments."

"an open appointment for the day.".

"fitting round what people need instead of everyone fitting round the doctor's surgery."

Transport and Logistics

- A **spectrum of possibilities** depending on identified need.
- Reimbursed/paid → NHS/voluntary transport → taxis.
- Changing the site of care (see **flexibility).**
- **Accompaniment** (logistical and advocacy).
- **Systems for access**: ***offered***, minimal gatekeeping, easy to use.

"Perhaps provide a taxi or bus tickets and things."

"do the journey [with them] [...] make sure the patient is safe"

"Getting people a bus pass or working out where we can see them if they can't get to us."

"Having somebody support me with getting to the appointments was really key because that just brought my anxiety down."

"In my own house, I'm in me own comfort zone, so I feel safer."

Contact around appointments

- More than just reminding, but **reminders** are important – stepped, person-centred approach.
- Personalised, exploratory, **invitational** contact.
- Identify and **offer support** with immediate barriers.
- Contact afterwards to follow up.
- Patients having **ways to 'reach in'** to services easily.
- <u>No support</u> for 'nudging', coercing or punitive contact.

"help reduce anxiety […] if they know exactly what the appointment is going to entail,."

"If someone doesn't turn up, we'll try and phone them, we'll try and speak to them"

"[It's] nice to be reminded. But that's not going to make any difference if it's really awful and I'm dreading it and I'm anxious, and I haven't got much money and it's a crappy day"

"Give them a ring and check that they're still OK. Remind them that I'm seeing them. Just make sure everything's OK in a friendly kind of way.'"

"what is the best way to contact a patient?"

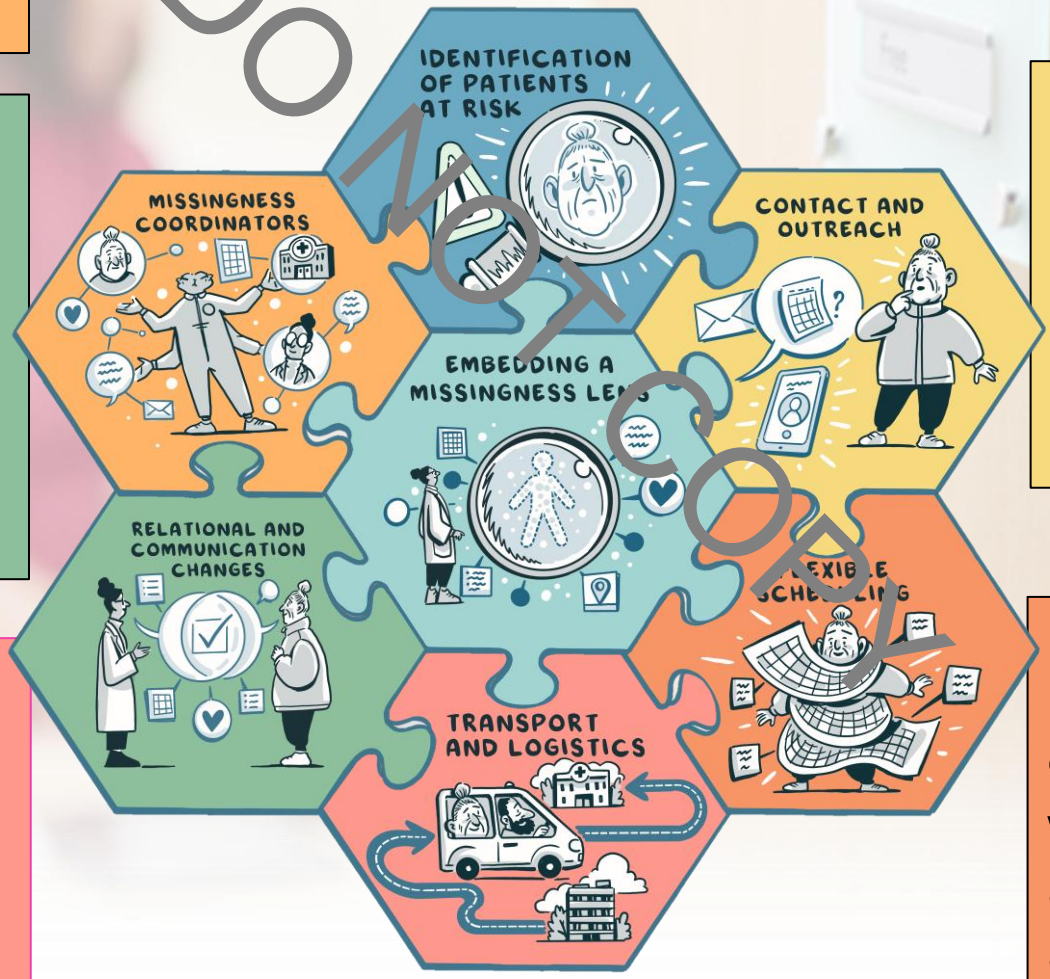
"A wee text is important"

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

IHAGP findings and evaluation

- Theme 3 most commonly chosen (52)
- 7000+ extended consultations
- Training events and resources shared
- Impacts on understanding, approaches, practice policies, outcomes (for patients, teams, systems)
- Evaluation Report
- Infographic

[Slides acknowledgement Dr Carey Lunan]

Template letter IHAGP

Dear [Patient's Name],

We're sorry you weren't able to make it to your appointment with [Clinician's Name] on [Date]. We hope everything is okay.

We understand that many things can make it hard to attend appointments — from health issues or family responsibilities, to stress or worries about coming in. Whatever the reason, please know we're here to support you, not to judge.

We'd really like to talk with you about how we can make it easier for you to get the care you need. If you're happy to, please get in touch with us or pop into reception to arrange a time to speak with our [Practice Manager / Community Links Worker / Admin Team Member / Doctor / Nurse].

You can call us on [Phone Number], or speak to us in person — whichever feels easiest for you.

We'd be grateful to hear from you by [Date – two weeks from letter]. If we haven't heard from you by then, someone from the team may give you a call or send a message to check in and see how we can help.

Scottish Health Policy developments

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 here on the Missingness Interventions, University of Glasgow webpage

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