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Applying a missingness lens to healthcare

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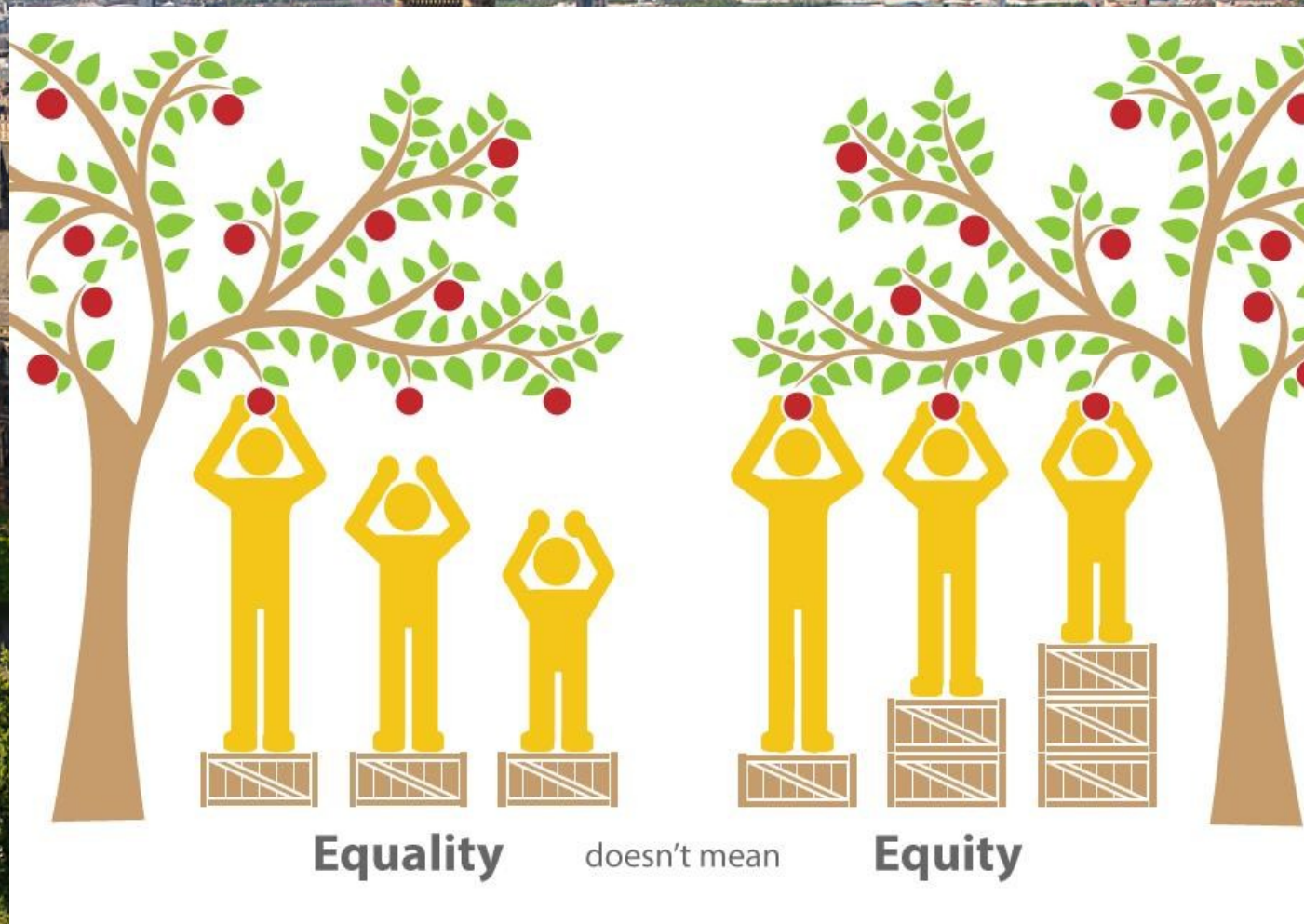
Presentation Outline

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



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The importance of equity 1



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



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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



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

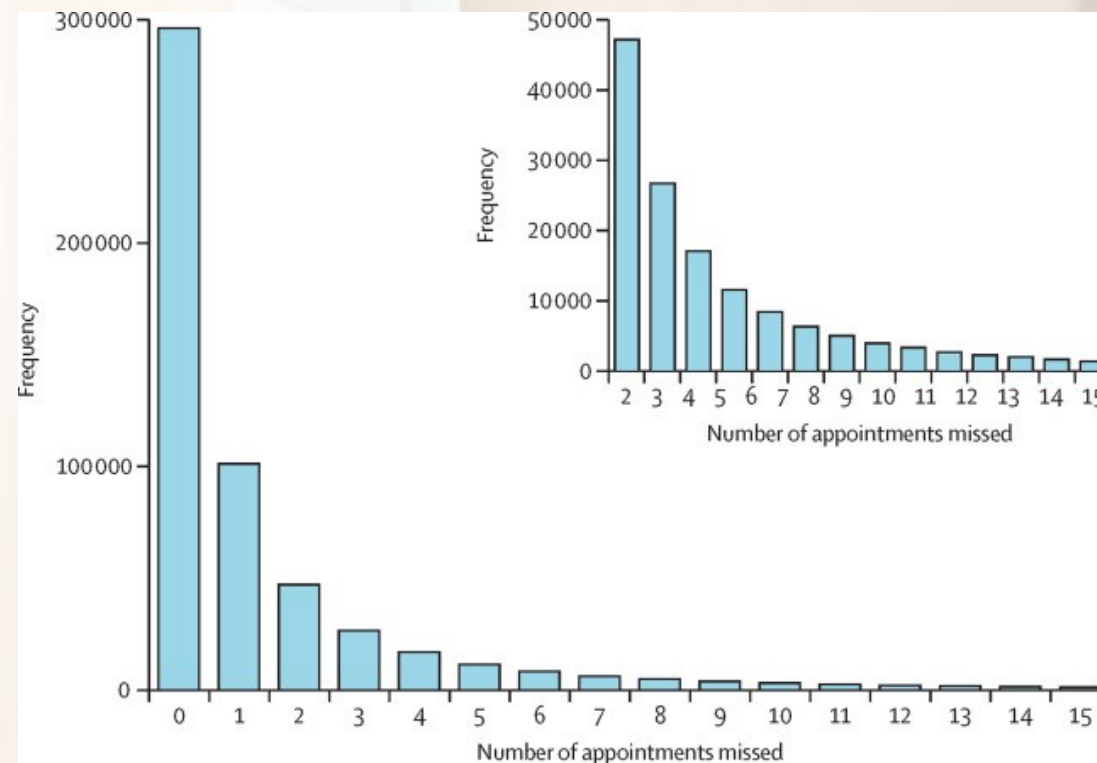
9 177 054 consultations

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)



Patient demographic factors

- Most socio-economically deprived (**SIMD 1**) patients most likely to miss appointments (RRR 2·27, 95% CI 2·22–2·31)
- Most remotely located patients least likely to miss appointments (RR 0.37, 0.36–0.38)
- Patients aged **16–30 years** (1·21, 1·19–1·23) & **older than 90 years** (2·20, 2·09–2·29) more likely to miss appointments
- Effect of gender small
- Ethnicity poorly recorded (2.69% all records)

(Ellis, McQueenie et al Lancet Public Health 2017)

GP practice demographic factors

- **Appointment delay 2–3 days** (RRR 2.54, 95% CI 2.46–2.62) most strongly associated with non-attendance
- **Urban GP practices** more strongly associated with missed appointments
- **More SE deprived patients registered with GP practices in more affluent settings have the highest risk of missing appointments**

(Ellis, McQueenie et al Lancet Public Health 2017)



Patient and practice demographics

- **Practice factors have a larger effect** than patient factors but a model combining both patient and practice factors gave a higher Cox-Snell pseudo R^2 value (0.66) than models using either group of factors separately (patients only $R^2=0.54$; practice only $R^2=0.63$) (Ellis, McQueenie et al Lancet Public Health 2017)

Morbidity and mortality

- Patients with **more long-term conditions** have increased risk of missing GP appointments (controlling for number of appts made)
- Patients missing appointments were at much greater risk of **all-cause mortality, the risk increasing with number of missed appointments** (independent of morbidities)

(McQueenie et al BMC Medicine, 2019)

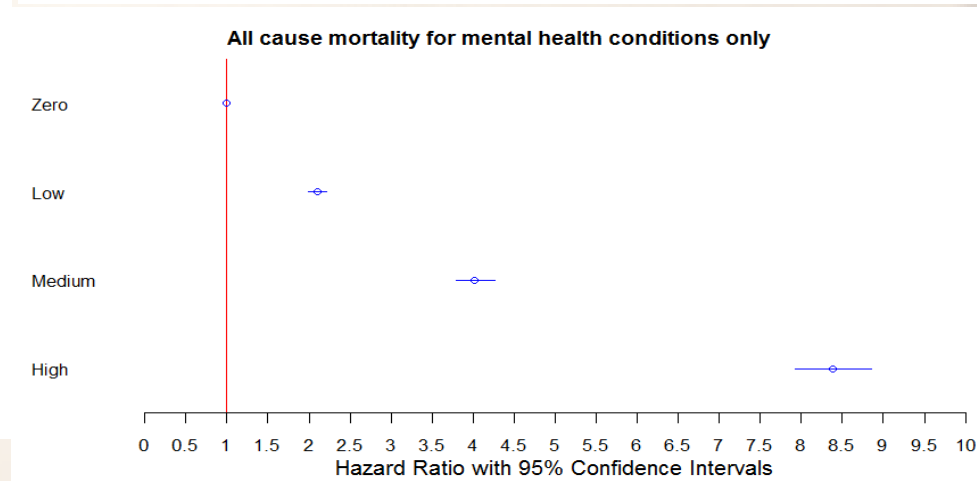
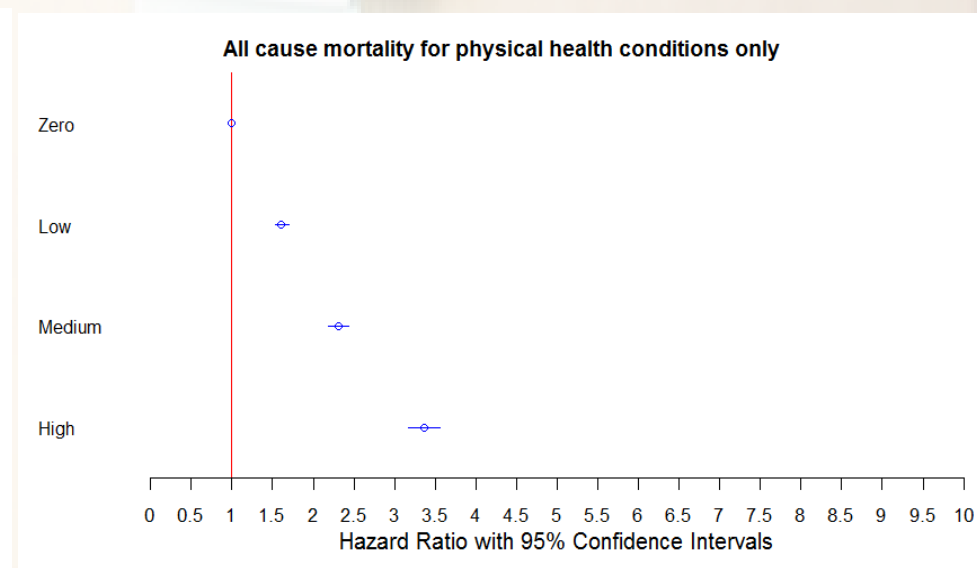
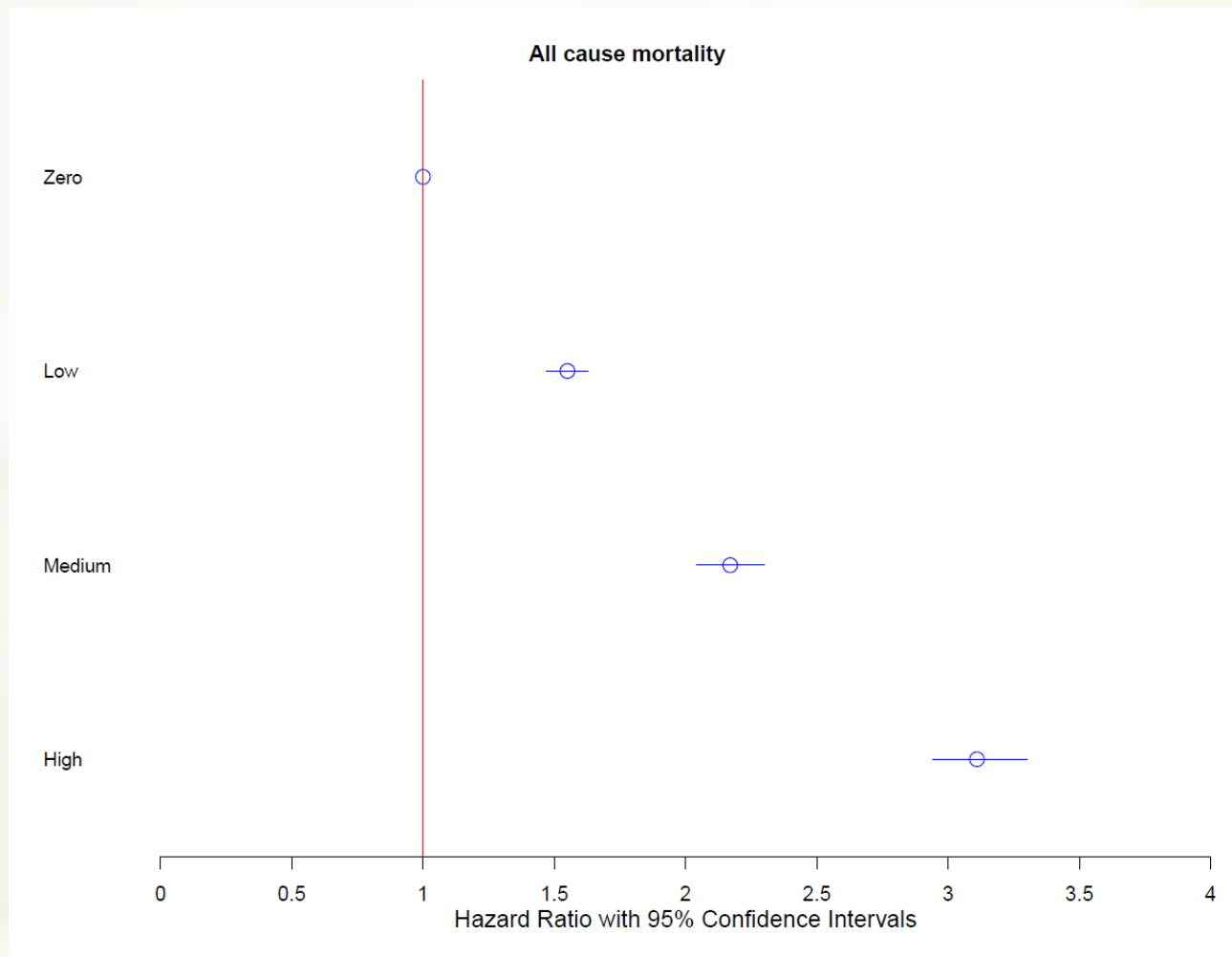
Shocking mortality

- Patients with **long-term mental-health conditions missing >2 appointments per year** had **>8x** risk of all-cause mortality compared with those who missed no appointments
- These patients died at a **younger age**, and commonly from **non-natural external factors**
- **Missing appointments repeatedly seems to be a powerful marker for greatly increased risk of mortality, particularly among those without physical long-term conditions** (after adjustment for all other mortality risks)

(McQueenie et al BMC Medicine, 2019)

Risk of death

Cox regression: adjusted for age, sex, demographics, practice factors and number of long-term conditions (McQueenie et al BMC Medicine, 2019)

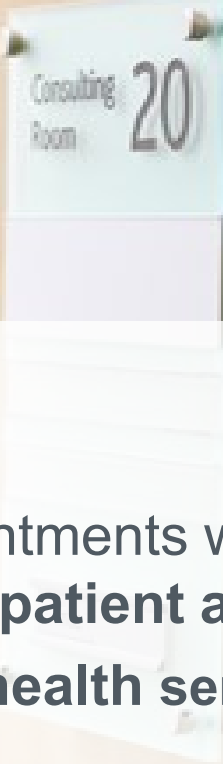


Hospital utilization

- Patients missing **high numbers** of GP appointments were **higher users** of **hospital outpatient** (RR 1.90, 95% CI 1.88-1.93)* especially mental health services (4.56, 4.31-4.83)
- and **inpatient care** (general 1.67, 1.65-1.68, maternity 1.24, mental health 1.23, 1.15-1.31), compared to patients missing no GP appointments
- **Emergency department use was the same across all groups** (1.00, 0.99-1.01)

*negative binomial regression modelling controlling for age, sex, SIMD and number of long-term conditions.

(Williamson et al Plos One 2021)

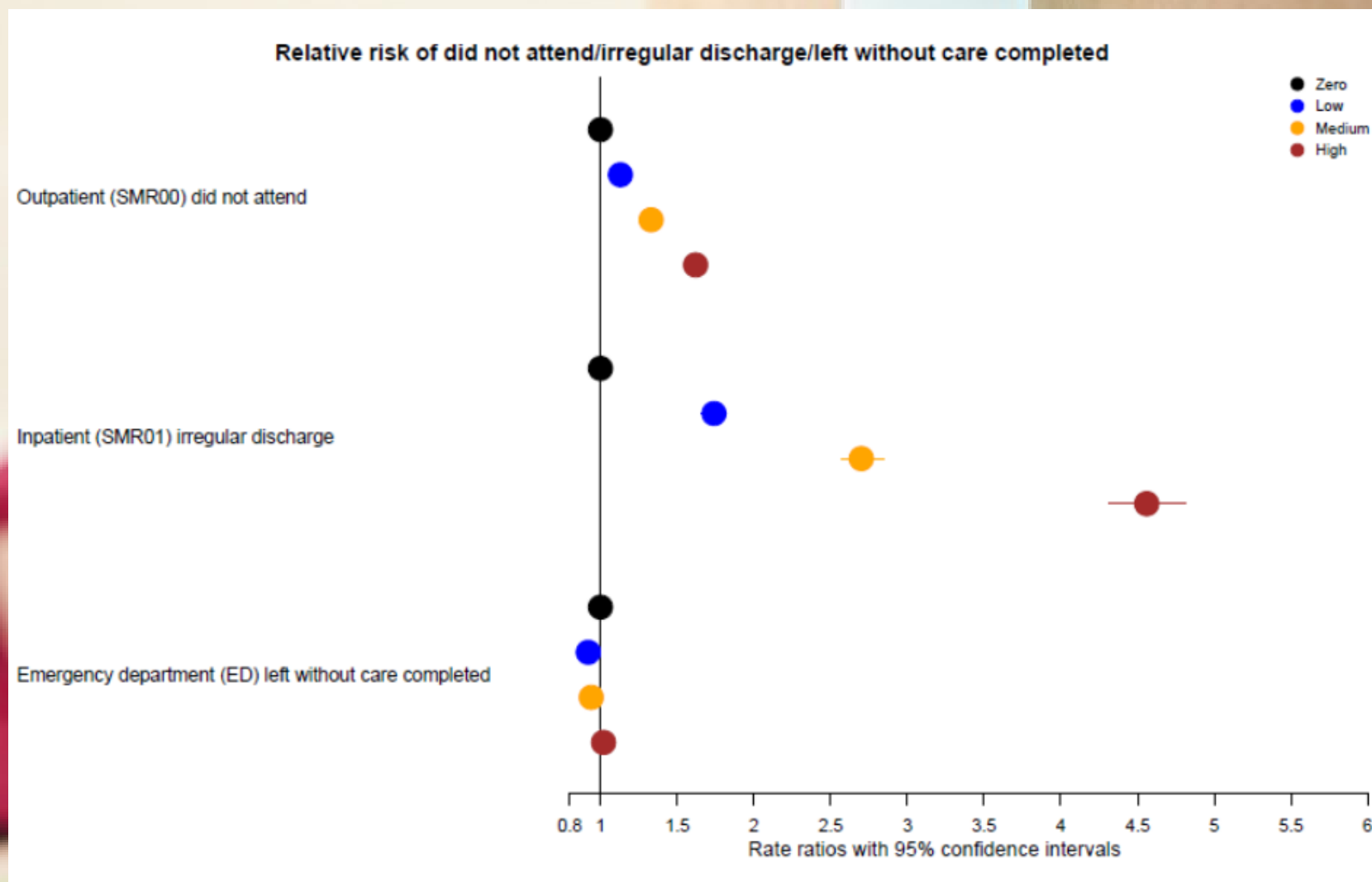


Hospital missingness

- Patients who had patterns of high missed GP appointments were **more likely** (RR 1.62, 95% CI 1.60-1.64)* to **miss hospital outpatient appointments**
- A **much higher risk** of non-attendance for **mental health services** (7.83, 7.35-8.35).
- Patients with high missed GP appointments were **more likely** (4.56, 4.31-4.81) to experience an **‘irregular discharge’ from inpatient care**
- No difference for ED ‘left before care complete’ between GP missed appointment category (1.02, 0.95-1.09)

*negative binomial regression modelling controlling for age, sex, SIMD and number of long-term conditions.

(Williamson et al Plos One 2021)



(Williamson et al Plos One 2021)

Life course social context

Patients at higher risk of missingness are more likely to have

- an ACE recorded in their GP record (Williamson et al BJGP Open 2020)
- From education linked data:
 - reduced school attendance
 - higher levels of school exclusion
 - lower educational attainment (McQueenie et al BMC Medicine 2021)

Epidemiology key conclusions

- **Patients** at high risk of missingness are characterized by poor health, higher treatment burden, complex social circumstances and have higher premature mortality
- **General practice appointment scheduling** and context is important
- **Patterns of missingness persist across secondary care** outpatients and inpatient 'irregular discharges'; patients are NOT seen in ED instead
- **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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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

- 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)



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- **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.
- 3/4. 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

Patient 'responsibilisation'



Shallow, monocausal perspective



Technical, practical, logistical



Standardised, service-oriented



Biomedical models of healthcare



Hierarchical, service-oriented solutions



A missingness lens

Services committed, resourced, incentivised to identify and address barriers

Complex causality for individuals, in contexts (tailoring)

Safety - structural, cultural, relational, psychological

Proportionate universalism and positive selectivism

Condition Competency, addressing SDOH, poverty, & marginalisation

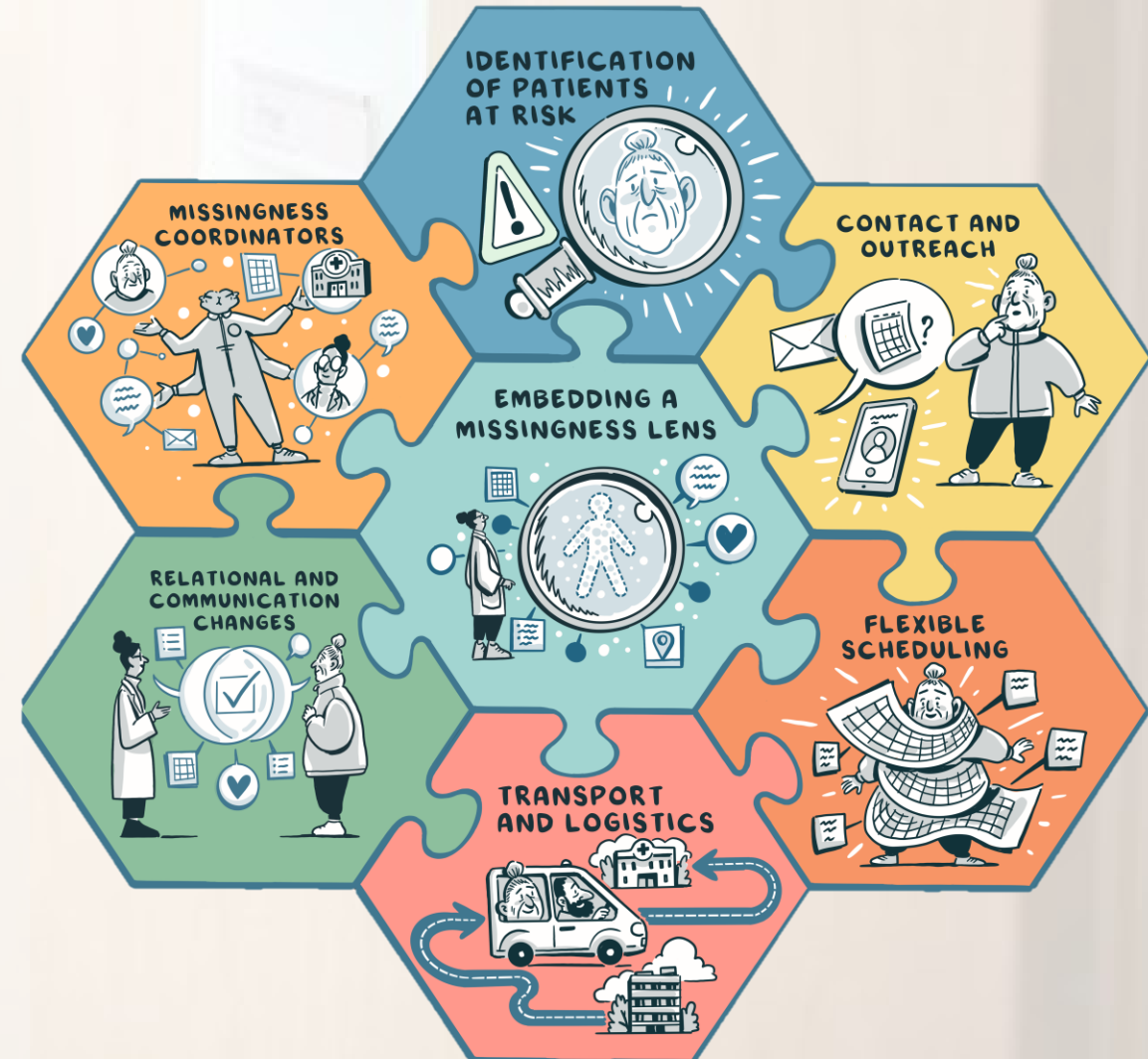
Person-centred approaches

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.

“acceptance that they need to do something differently”

“changing the way (NHS staff) think”



“the key to everything”

“culture change”

“perspective shift”

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.
- No support 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

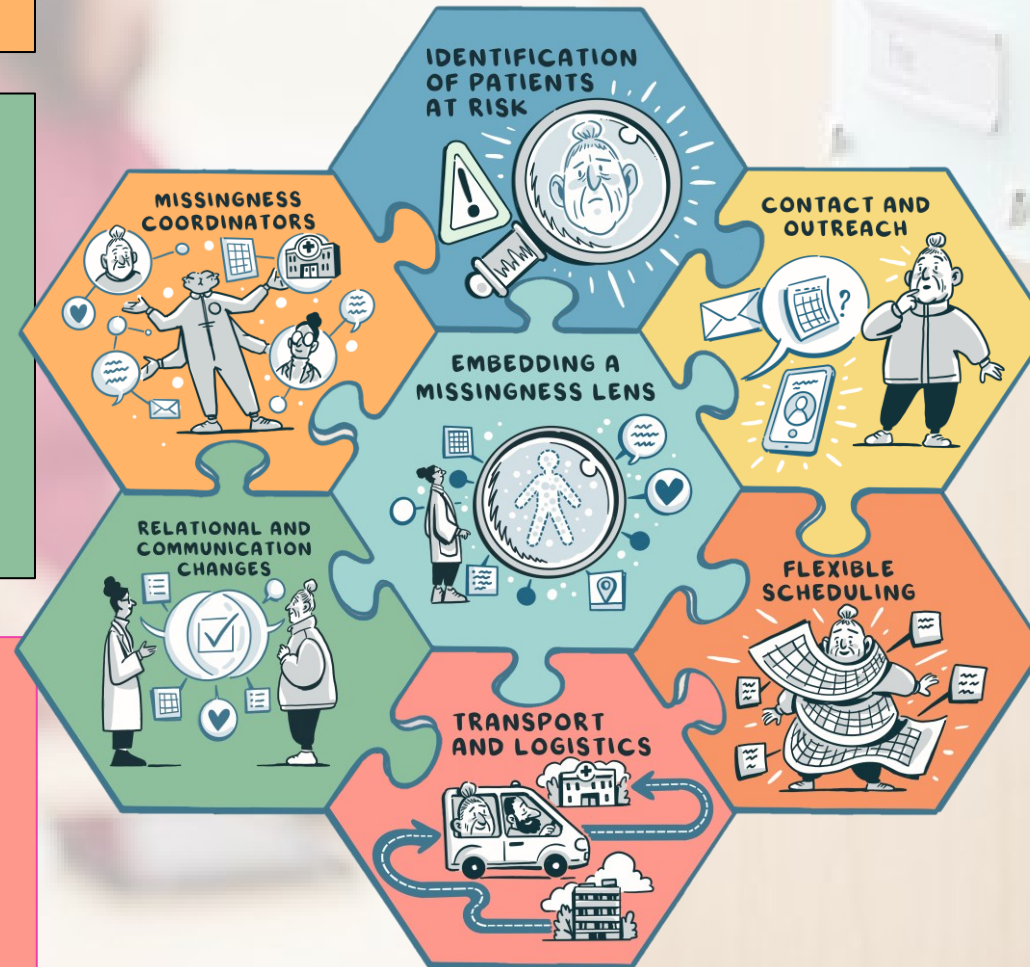
Identifying and tracking local patterns and trends.
Exploring barriers while building relationships.
Building a picture – individual + collective.

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.



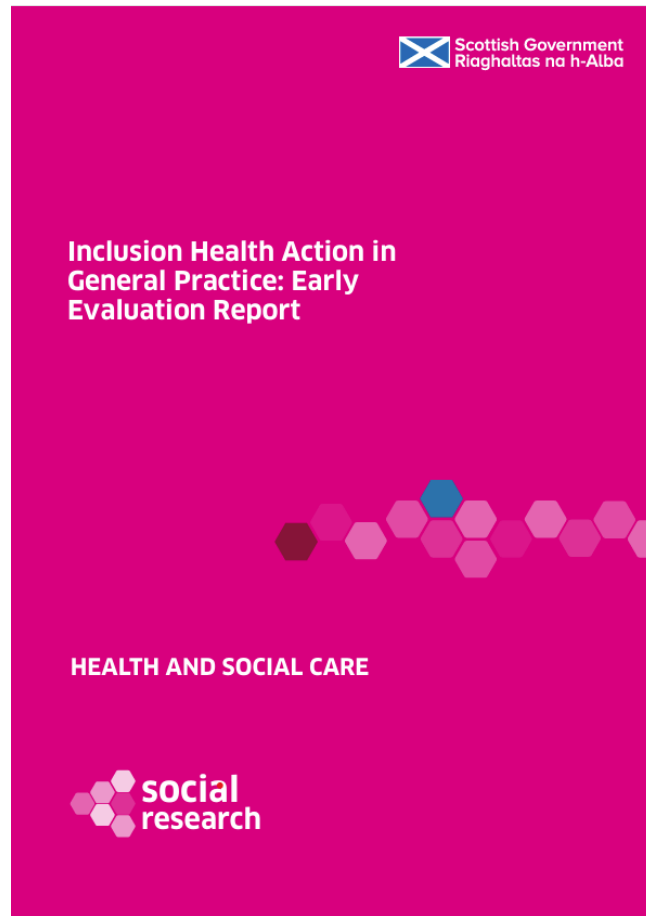
Applying a Missingness lens in **Service Design**: Inclusion Health Action Fund in General Practice

- In March 2023, IHAGP was developed in response to one of the key recs from the SG [Primary Care Health Inequalities Short-Life Working Group](#):
- Additional funding to around 70 SE deprived-area practices across Glasgow area
- To support specific actions to tackle challenges associated with health inequalities within their patient populations under 3 key areas:

1. Building inclusive patient engagement/patient participation
2. Enhancing workforce knowledge and skills for health inequalities
3. **Enabling proactive outreach and extended consultations***

* Specifically with patients who are at high risk of physical or mental ill health due to poverty and inequality

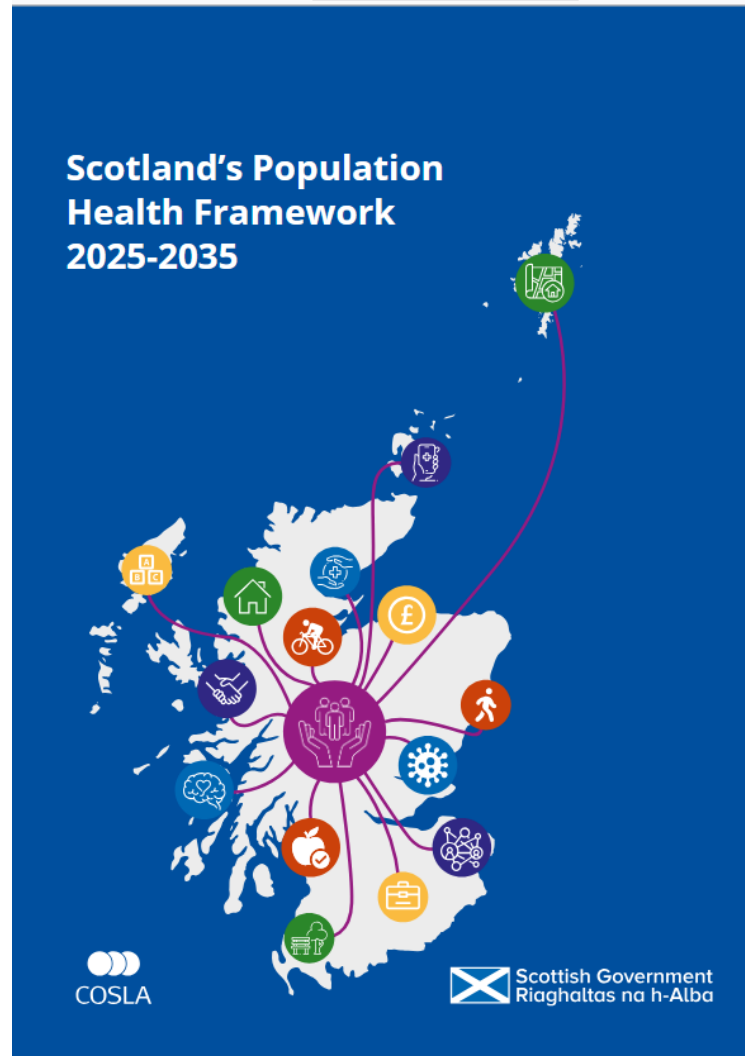
IHAGP findings and evaluation



- 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]

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

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

