

Developing a Minimum Standards Framework for the involvement of individuals with Lived Experience in Gambling Research

by

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Intro and structure



- Gambling in the UK
- What is Lived Experience in research?
- Minimum Standards Framework
- Other projects
- What next?

Gambling in the UK



How many people gamble?

| Survey | Timeframe | Age | Prevalence |
|--------------------------|--------------|-----|------------------------|
| BGPS 1999 | Past Year | 16+ | 72% |
| BGPS 2007 | Past Year | 16+ | 68% |
| BGPS 2010 | Past Year | 16+ | 73% |
| HSE 2012 | Past Year | 16+ | Male 68% Female 61% |
| HSE 2015 | Past Year | 16+ | 63% |
| HSE 2018 | Past Year | 16+ | 54% |
| Gambling Commission 2023 | Past 4 weeks | 18+ | 48% |

Disordered Gambling

| Survey | Timeframe | Tool | Prevalence |
|---------------------|--|----------------|--------------|
| BGPS 2010 | Past Year | DSM-IV PGSI | 0.9% 0.7% |
| HSE 2015 | Past Year | DSM-IV PGSI | 0.7% 0.6% |
| HSE 2018 | Past Year | PGSI | 0.4% |
| Gambling Commission | Past Year (to Sept 20) Past Year (to Sept 21) | PGSI PGSI | 0.6% 0.3% |
| HSE 2021 | Past Year | PGSI / DSM-IV | 0.4% |

Costs of Gambling

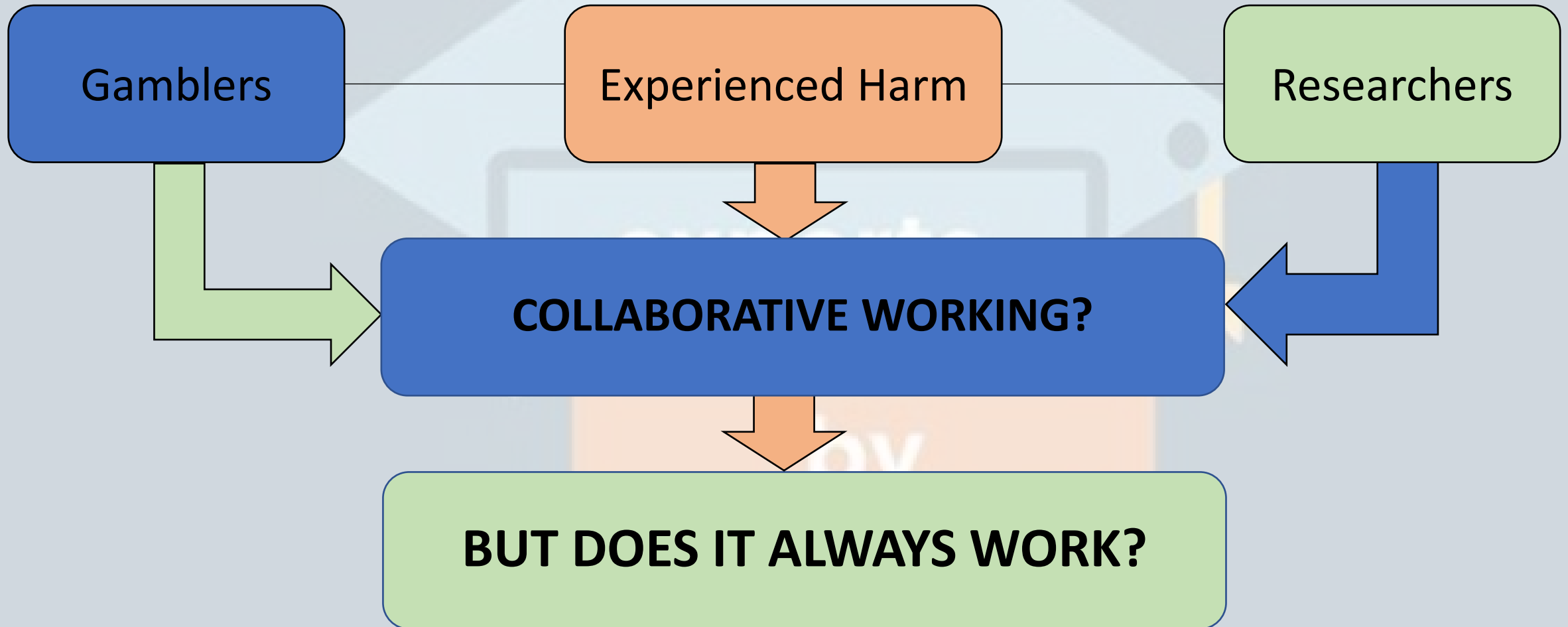
The economic cost of gambling-related harm in England: evidence update 2023

Table 1. Estimated excess cost of harm associated with gambling in England, by type of harm and type of cost

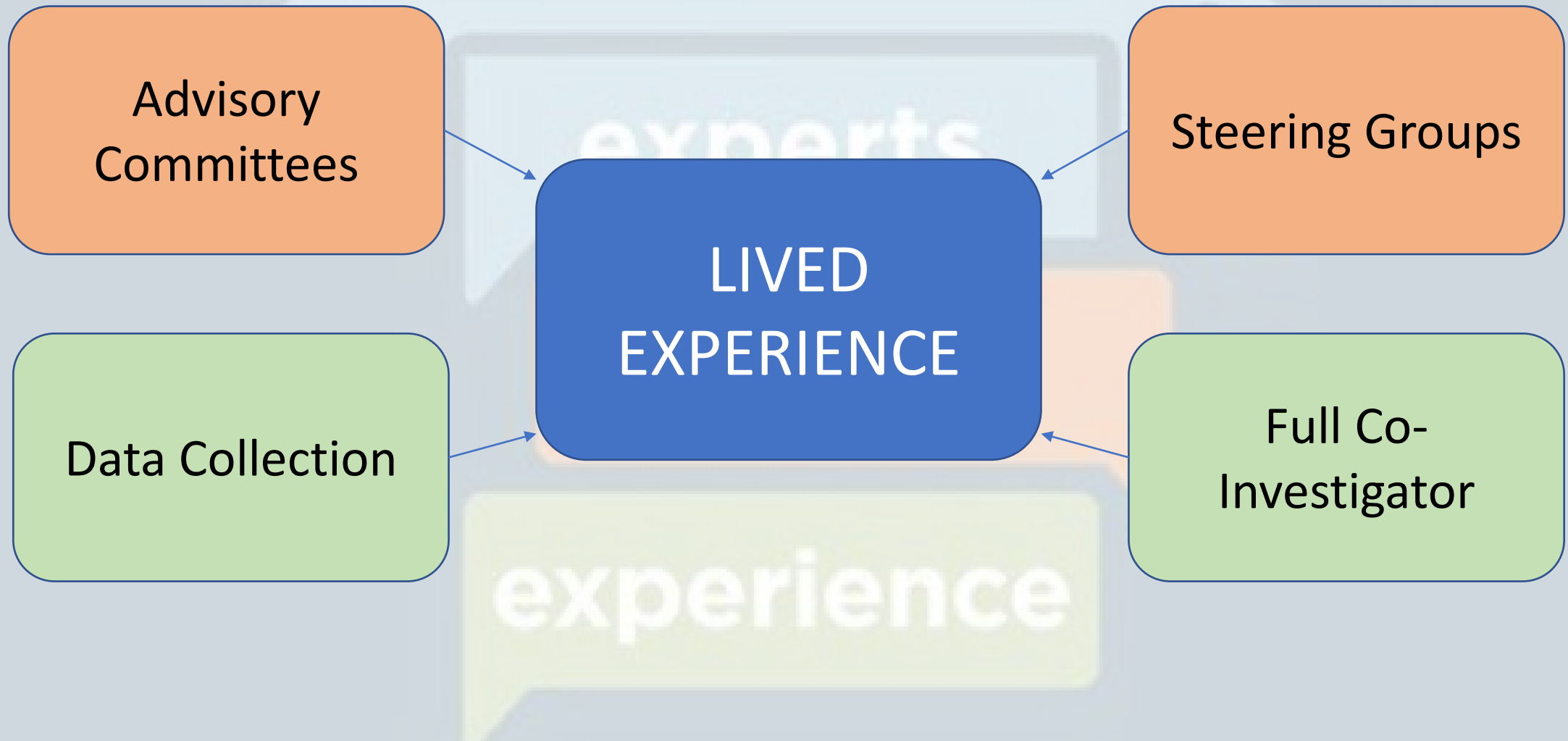
| Type of harm (or domain) | Sub-domain | Cohort | Government (or direct) costs (£ millions) | Wider societal (or intangible) costs (£ millions) | All costs (£ millions) |
|--------------------------|------------------------|--------------------|--|--|---------------------------|
| Financial | Statutory homelessness | Adults | £49.0 | N/A | £49.0 |
| Health | Deaths from suicide | Adults | N/A | £241.1-£961.7 | £241.1-£961.7 |
| Health | Depression | Adults | £114.2 | £393.8 | £508.0 |
| Health | Alcohol dependence | Adults | £3.5 | N/A | £3.5 |
| Health | Illicit drug use | 17 to 24 years | £1.8 | N/A | £1.8 |
| Total health harms | All health sub-domains | All health cohorts | £119.5 | £635.0-£1,355.5 | £754.4-£1,475.0 |
| Employment and education | Unemployment benefits | Adults | £77.0 | N/A | £77.0 |
| Criminal activity | Imprisonment | Adults | £167.3 | N/A | £167.3 |
| Excess cost (£ millions) | All sub-domains | All cohorts | £412.9 | £635.0-£1,355.5 | £1,047.8-£1,768.4 |

Notes: Figures may not sum due to independent rounding. N/A means that analysis was not undertaken.

What does this mean for research?



What is Lived Experience in Research?



What does Lived Experience bring to Research?



Knowledge and Experience

Different Perspective

Reality Check

Access and Recruitment

Credibility

Accessibility

What do we do wrong?

- Our previous work in this area has identified 3 major areas where researchers sometimes fall short:





experts

by

experience

Minimum Standards Framework

What are the key components of the MSF?

Engagement

Training
Support

Remuneration

Aftercare

Credit and
Dissemination

Evaluation

experience

MSF – Draft 1

A Minimum Standards Framework for including Lived Experience in Gambling Research

The importance of the contribution of Lived Experience (LE) in research is growing. However, despite the recognition of the importance of LE throughout the research process, significant barriers and concerns around LE engagement still remain. Accordingly, in collaboration with LE Experts and gambling academics, the Academic Forum for the Study of Gambling (AFSG) Outreach Committee have developed a Minimum Standards Framework (MSF) to guide both researchers and LE experts on maximising the potential of collaborative relationships.

Two Focus Groups

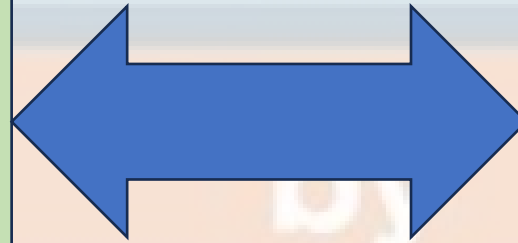
Group 1: Lived Experience

6 participants
(3 men, 3 women)

3 Gamblers, 2 Affected
others

Nearly 2 hours

Paid £10 voucher



Group 2: Academics

4 participants
(2 men, 2 women)

Variety of backgrounds and
career stages

Just over one hour

Paid £10 voucher

LE Focus Group – Key Suggestions

Engagement

- Even earlier engagement – set the research agendas
- LE have ideas that academics won't think of
- But LE will only work on what they are interested in
- Mentors
- Variety of people / experience / EDI

Remuneration

- Costs up front – trains / childcare? Offer don't ask
- Vouchers or cash – either – let the person choose?? – flexible in project (tokenistic)
- Depends on role commitment
- Pay just for meeting or recovery time
- Should be commitment / project specific
- BUT do have to be careful with cash (benefits etc)

LE Focus Group – Key Suggestions

Aftercare

- Researchers aren't the best people to do it
- Understanding the needs of the individual
- Level of suitability (assessment)
- But hard to reject / judge

Other thoughts

- Down to individual. Discuss. Be flexible
- LANGUAGE
- Lived experience board
- Involvement from start to finish
- Living document to be consistently assessed and updated

Academic Focus Group – Key Suggestions

Levels of engagement

- Don't force it; over prescriptive – involvement for the sake of involvement
- Suitability for project
- Disagreement – LE can be involved in EVERY project
- Agree outcomes beforehand
- Industry relationships? – down to individual researchers
- Type of lived experience of gambling – don't mix
- Slow down the process / overworking academics

Remuneration

- NIHR rates – not enough
- Lazy to default to these – work it out from minimum wage
- But paying too much is viewed as coercive

Academic Focus Group – Key Suggestions

Evaluation

- Again, project specific. Good on big grants, not so much relevance to smaller things?

Other thoughts

- Language considerations
- Trust works both ways (sharing private materials)
- Less of 'us and them'
- Respect goes both ways
- Expectation management

MSF: Next Stage

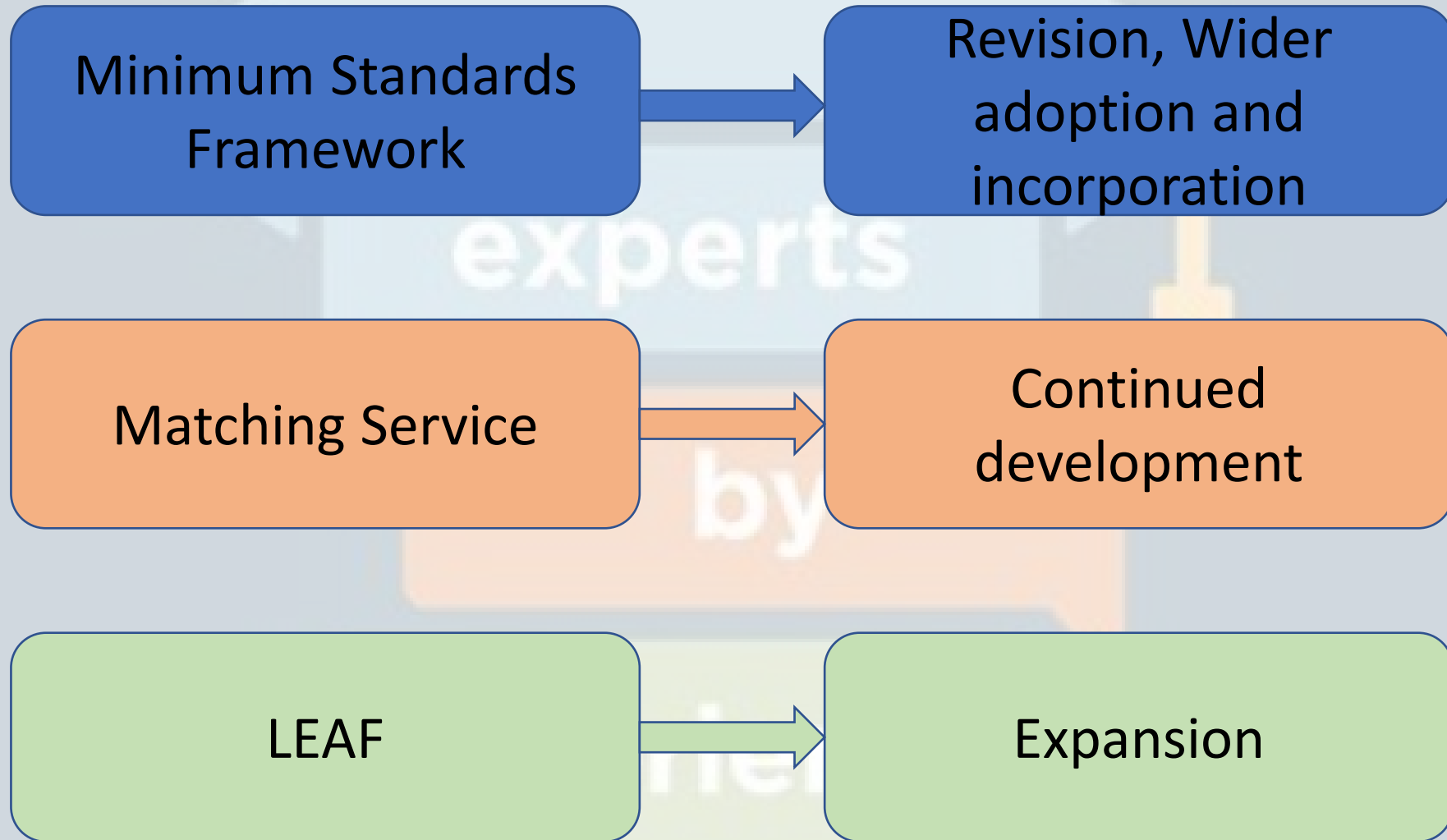
Refine the MSF based on focus group feedback

Conduct Stage 2 focus groups on revised document

Pilot implementation in a specific funding call



What next?



Thanks, funding, and questions

- Thanks to Greo for funding
- Collaborators: All the members of the LEAF panel: Kishan Patel, Claire Donegan, John Gilham, Julie Martin, plus Beverly Ostryhon, Matthew Young (Greo), and Simon Diamond (Swansea)
- Questions
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