An Exploration of the Evidence System of UK Mental Health Charities

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Giving Evidence

Enabling **giving** based on sound **evidence**

Contents

About the authors

Giving Evidence is a consultancy and campaign, promoting charitable *giving* based on sound *evidence*. Through consultancy, Giving Evidence helps donors and charities in many countries to understand their impact and to raise it. Through campaigning, thought-leadership and meta-research, we show what evidence is available and what remains needed, what it says, and where the quality and infrastructure of evidence need improving.

Giving Evidence was founded by Caroline Fiennes, a former award-winning charity CEO, and author of *It Ain't What You Give*. Caroline speaks and writes extensively about these issues, e.g., in the Stanford Social Innovation Review, Freakonomics, and the Daily Mail. She is on boards of The Cochrane Collaboration, Charity Navigator (the world's largest charity ratings agency) and the US Center for Effective Philanthropy.

Leonora Buckland has worked for a variety of organisations and projects in social entrepreneurship, social investment and philanthropy. She has been a consultant for the Skoll Foundation and Executive Director of the Venture Partnership Foundation. She helped to design the London Business School social entrepreneurship course for Professor Michael Hay. She has written articles for the Stanford Social Innovation Review on microfinance and European venture philanthropy. She has a 1st class degree from Oxford University, a Masters in International Economics from SAIS, Johns Hopkins University and a PhD from Oxford University.

Acknowledgements

Executive summary

Project Aims and Rationale

The project aimed to explore the 'evidence system' for UK mental health charities. An 'evidence system' comprises how evidence is produced, synthesised, disseminated, and used: who is involved in each of those four stages, why they do them, how work at each stage is funded, and what aids and hinders work at each stage.

This project sits alongside studies that Giving Evidence has conducted of other sectors to help charities and donors make better evidence-based decisions. It was commissioned by the AD Charitable Trust which funds UK mental health charities and is interested in evidence. We hope that the report and findings catalyse and inform a wider mental health charity sector discussion about practical ways to help mental health charities to make good decisions, by using and building the evidence-base for their work.

Method

Giving Evidence performed semi-structured qualitative interviews with 12 mental health service delivery charities of varying sizes / geography as well as qualitative interviews with four mental health sector experts. In addition we looked at some of the publicly available materials of the mental health charities we interviewed.

Giving Evidence recognizes the limitations of the study due to the small number of charities interviewed, potential bias in the selection of charities and limited timescale but hopes that this report can nonetheless serve as a useful starting-point for further exploration and discussion. Further work with more charities would be required to give greater confidence about the overarching findings.

Descriptions

The concept of an evidence system emerged from health and is useful for understanding what may need to happen to help mental health charities make more evidence-informed decisions.

Giving Evidence is aware that the term 'evidence' means different things to different people. We have used a fairly inclusive definition of evidence comprising: evaluation evidence (i.e., investigating causal links between activities and results); stakeholder evidence (e.g., user feedback); practitioner evidence (e.g., staff judgement) and contextual evidence (e.g., research into the prevalence or type of need).

For a fuller description of an evidence system and the definition of evidence used for this study, please see pgs. 10-12.

Findings

Outlined below is a summary of the current evidence system for mental health charities. It is applicable to the majority of charities interviewed (particularly small and medium-sized ones which are primarily service-delivery rather than campaigning or policy organisations). Please note that there is a wide range of experience amongst charities we interviewed, mainly determined by the size of the charities. In particular, these findings may not reflect the experience of some larger charities (such as Mind in England and Hafal in Wales), who are leading the field in producing, disseminating and using evidence. Moreover, these findings do not apply to charities specialized in research and policy in mental health (such as the Centre for Mental Health) which we considered expert interviewees.

- **Production of evidence:** mental health charities have focused on producing practitioner and stakeholder evidence - obtaining feedback from users and ensuring that the lived experience voice is heard and respected. However, until recently service delivery charities had conducted few rigorous impact evaluations. Indeed, there is relatively little research produced by charities specifically into the causal effects of their interventions. Since some charities are not using the academic research available regarding the effectiveness of different interventions, this means that services may not be based on robust scientific evidence. This appears to be primarily a resource problem - whilst most charities appear committed to evaluation, evaluations are done on very small budgets. With budgets tightening, often research and evaluation spend is being jeopardised. However, there is increasing demand from funders for evidence as well as a growing internal drive among charities to produce and use evidence. Encouragingly, some larger charities are dedicating more funds to evaluation research, growing more sophisticated in its implementation / commissioning and collaborating with universities / academics, the public sector and funders to produce it.[1] There have also been several recent high-profile evaluation projects which provide best-practice examples and indicate an evolving field.

- **Synthesis of evidence:** evidence produced by charities, outside of academic partnerships with universities, does not appear to be routinely synthesised or included in systematic reviews. Mental health charities are doing their own synthesis and analysis of third-party research where they have the skills / resources.

- **Dissemination of evidence:** mental health charities often share their research via their websites or annual reports. There does not seem to be a problem of mental health charities consciously or selectively withholding evidence that they produce. However, Giving Evidence found that apart from a few of the largest charities, most mental health charities do not share their evidence in a clear or full manner. Interviewees suggested that the main factors here are fear of sharing information with competitors, the perception that their evidence is of limited relevance to other organisations, and lack of resources / incentive to do so. In addition, few charities disseminate their material in journals or through conferences, apart from where an academic partnership is involved. Dissemination of evidence from academics to the practitioner charities is also currently fairly weak – charities often hear about interesting research through informal means and word-of-mouth. There does not appear to be a go-to place to access relevant third-party research about the kind of interventions which mental health service delivery charities run.

- **Use of evidence:** evaluation evidence produced by charities seems to most often be used for funding / marketing purposes. Less frequently, particularly by small and medium-sized charities stretched for time, is it applied to design / improve services or for organisational learning. Stakeholder evidence including user research and satisfaction surveys do seem to be more actively used and acted upon. Mental health charities struggle to find and then apply relevant evidence produced by third parties such as academics or other service delivery charities to their decision-making. Charities sometimes use evidence produced or

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1 Please note that Giving Evidence does not wish to imply here that there are not academics within the charity sector nor that partnerships with universities / academics are the only means to deliver rigorous research. We include these examples because we heard during our interviews that collaborations with universities and academics are proving fruitful and leading to mutually beneficial knowledge-sharing between sectors. However, we acknowledge that in some charities, there are already academics in-house who have the skills to lead charity research.

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synthesised by mental health policy charities such as the Centre for Mental Health and the Mental Health Foundation. Such organisations play an important role in producing and / or making evidence digestible and usable for the sector. However, we found few charities with routine / formal processes for collecting and processing relevant external evidence. A significant barrier to greater use appears to be that some charities perceive the evidence base for psychosocial mental health interventions to be fairly weak. On this point, there seems to be some disagreement within the sector since many experts and a few charity interviewees stated that there is plenty of external evidence that could be used. Mental health charities mentioned several problems with the existing evidence:

a) availability: it can be hard to find and / or unclear in its description and / or too expensive to access if it is in paywalled journals; and

b) applicability: it is not practical enough and charities doubt its relevance to their specific interventions. In addition, some smaller and medium-sized charities without specialised research employees lack the time and / or skills to find, evaluate and process external evidence.

There are important new initiatives which aim to address some of the issues affecting the evidence system for mental health charities, including organisations synthesising and / or bringing together relevant research (e.g., the What Works Centre for Wellbeing, Mental Elf), new players focused on improving the evidence base for the mental health sector (e.g., MQ: Transforming Mental Health) as well as networks bringing together mental health charity research funders (e.g., the Alliance of Mental Health Research Funders).

Conclusion

Whilst the number of charities interviewed was small and the range of experience varied, we identified some important gaps in the evidence system, which need to be explored and discussed further within the sector. In particular: more rigorous evaluation research needs to be produced about the effectiveness of charities' interventions; mental health charities could make more use of the academic literature that already exists; and, more evidence could be actively disseminated within the sector to enable greater learning.

Although there is growing interest and enthusiasm for producing, disseminating and using evidence by mental health charities, and some best practice examples to inspire the sector, the major barrier to improving the evidence system is resource (see Box 1 below).

Indeed, improving the evidence system for mental health charities requires the collaboration of many other players beyond the charity sector: central government; local government and commissioners; private funders / foundations; and, academics. Each has an important role to play. There are some encouraging signs that the English central government is prioritising mental health research spend which may improve the amount and quality of evidence that can be produced and used by charities.[2] Moreover, there is a growing number of collaborations between academics and mental health charities which could prove to be fruitful.

Recommendations

Further work is needed to support the mental health charity sector to become more evidence-based. This report provides a list of recommendations (outlined below but discussed in more detail on pages 39-43) for how the evidence system could be improved. These need to be developed with the sector.

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2 We heard, however, that the majority of funding is likely to go to universities rather than charities. One charity was concerned that this increased funding may not lead to more resources for important user-led charity research.

1. Work together with other bodies and academics to prioritise unanswered questions relating to the mental health charity sector evidence base. This can ensure that research resources are directed to where they are most needed, e.g., to improving the evidence for key interventions.
2. Co-produce research with the academic sector on those priority questions.
3. Investigate how funders can support initiatives to reliably answer the important priority questions.
4. Improve common measurement of the impact of mental health charity interventions.
5. Increase the synthesis of evidence relating to mental health charity sector interventions.
6. Improve the clarity of research reporting by the mental health charity sector.
7. Strengthen the infrastructure around the storing of relevant charity sector evidence.
8. Identify what is needed for mental health charities to make greater use of the existing research.

Box 1: Mental Health Is Very Under-Resourced, Particularly Research[ii]

MH as Proportion of the UK's Health Problem, Health Delivery budget and Health Research Budget
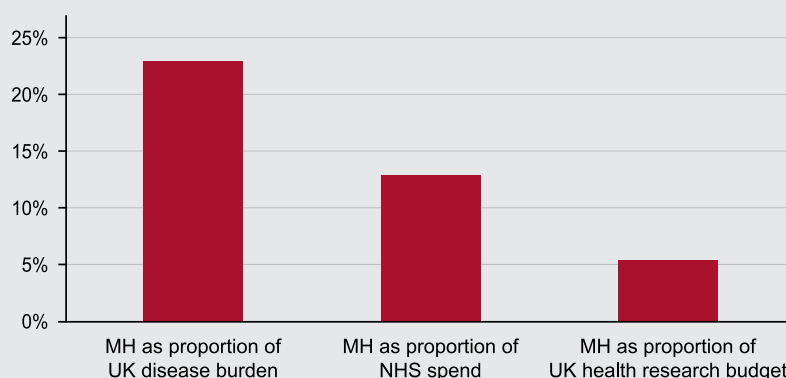
Charitable spend per beneficiary for various causes (UK)
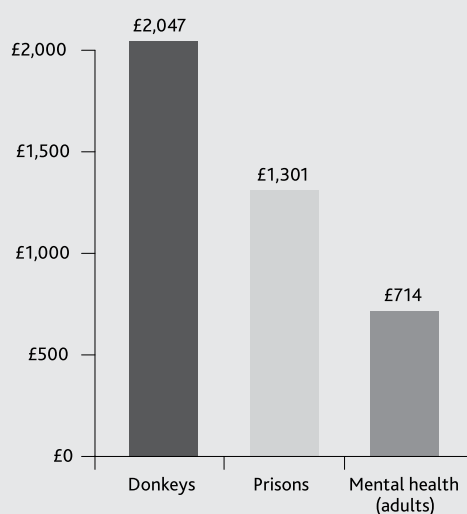
Introduction

About Giving Evidence

Giving Evidence aims to improve the outcomes for beneficiaries of the voluntary sector by helping charities and donors to make better evidence-based decisions. For this to happen, evidence needs to be: 1) a high quality; 2) available / published; 3) clear; 4) readily findable; and 5) used correctly.

Giving Evidence has studied the use of evidence by donors and charities: it has looked at improving clarity and usefulness of research by charities in criminal justice[3] and at what education in less developed countries can learn from evidence-based medicine.[4] It has recently published a systematic review of evidence about outdoor learning with University College London. Caroline Fiennes, who founded Giving Evidence and who has worked for more than a decade in improving charities' and donors' performance, raises awareness about the importance of evidence in both the charity sector and mainstream press and at events.

Giving Evidence does not claim specific expertise or knowledge of the mental health sector and thus the project has been a learning journey. Giving Evidence does have a broad understanding of evidence in the charity and medical sectors which it has used to inform and guide this project. Giving Evidence hopes that the findings from the project will be used, discussed and digested by the mental health charity sector which has the depth of knowledge and understanding about mental health required to determine and bring to fruition future initiatives.

About the AD Charitable Trust

The AD Charitable Trust was set up in 2002 and funds work in the United Kingdom to support disadvantaged people, helping them both practically and in building esteem, so they can reach their full potential. It hopes to add value to charitable organisations, through commissioning studies, collaboration, and sharing any learning. The AD Charitable Trust is particularly interested in evaluation, hence why it has supported this project. It only supports services where evaluation is integral. It is particularly interested in encouraging the use of longer-term evaluation / impact data (as opposed to outcome data) and is prepared to fund evaluation work in addition to delivery.

Project aims

The project aimed to understand the 'evidence system' of UK mental health charities with a view to identifying key opportunities and barriers to improving it. Giving Evidence hopes to prompt practical solutions to enable mental health charities to be more evidence-based. As a relatively small project, the scope was to provide an initial understanding / starting-point and a platform for actionable change, rather than an exhaustive analysis.

The concept of an evidence system[iii] emerged from health and is a helpful framework with which to understand the current situation regarding evidence in relation to mental health charities.

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3 Findings are summarised in the Giving Evidence report, '*Charities Research Infrastructure: Improving Clarity and Usefulness of Research by Charities in Criminal Justice*.' https://givingevidence.files.wordpress.com/2014/06/charities-research-infrastructure-oct-2014-published.pdf
4 Findings are summarised in the Giving Evidence report, *'Getting Better: what education systems in less developed countries can learn from evidence-based medicine'* https://givingevidence.files.wordpress.com/2014/05/getting-better-full-version-may-20141.pdf

Figure 1: Elements of an evidence ecosystem (adapted from Shepherd, 2007a)
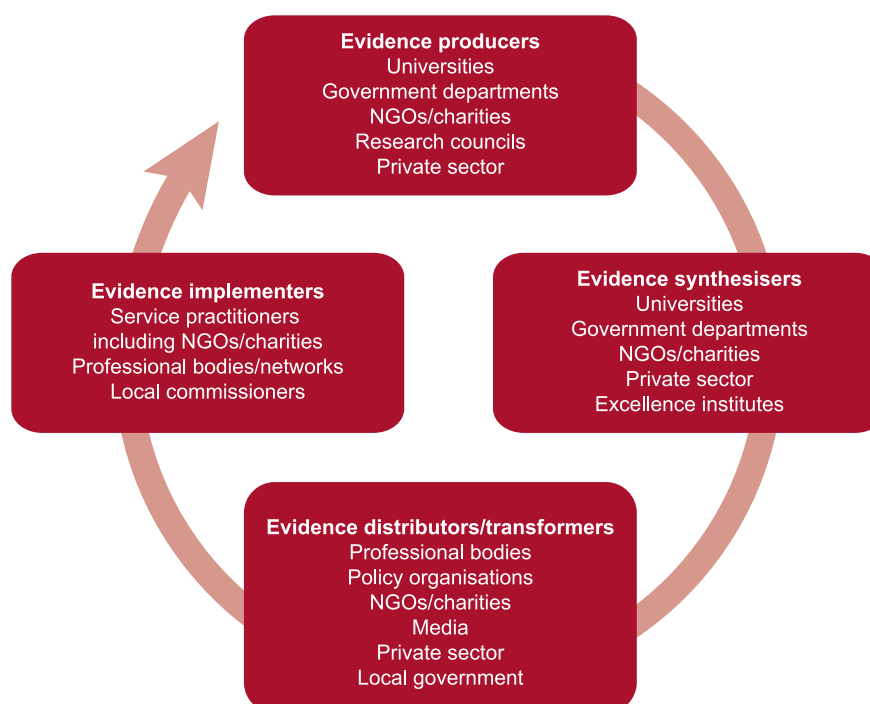
The objective of an evidence system is to enable good decisions. It should enable practitioners, policy-makers, funders, and others to (a) find any existing research, such as about the effectiveness of interventions for ameliorating particular situations, (b) compare those interventions, in terms of effectiveness, cost and cost-effectiveness: that in turn relies on being able to assess the quality of the research, (c) ascertain or estimate whether the intervention is likely to produce those same outcomes in the decision-maker's own context and (d) give the reader enough detail that they could replicate the intervention. A good evidence system also reduces waste (e.g., research into questions to which the answers are already known) simply by making the existing research findable and clear.

Table 1: Characteristics of a functioning evidence system

Evidence system stage	Key Characteristics
Production	• Large amount of high quality evidence is produced (normally means significant funding of research). • Both qualitative and quantitative methods are used. • Research is produced and addresses priority questions.
Synthesis	• Results are synthesised to account for conflicting results and results from different situations. This makes it easier for practitioners to see the weight of evidence, and conclusions most relevant to their situations.
Dissemination	• Research and synthesis reaches people who need it (normally practitioners and policy makers). • Research and synthesis are indexed and findable for users seeking it.
Use	• Practitioners and policy-makers use the research. This often means that there are aids for use e.g., plain language summaries, practice guidelines and checklists.

The project aimed to answer the questions outlined below:

- Production of evidence: how far and in what context do mental health charities produce evidence (what type of evidence is produced, why, who funds it and who conducts it?) What isn't produced and why not? Who else produces evidence that charities use? What are the key drivers and barriers to the production of evidence by charities?
- Synthesis of evidence: how is evidence produced by charities or others synthesised, by whom?
- Dissemination of evidence: how far do mental health charities publish clear reports on and disseminate the evidence that they produce? Where do they publish and why? Which dissemination channels are used? What aids and hinders the dissemination of evidence?
- Use of evidence: how far and in what context do mental health charities use evidence in their decision-making (meaning evidence produced by themselves, other charities or third-parties such as academics)? What are the key drivers and barriers to the use of evidence?

Falling outside the scope of this project was analysis of:

- the quality of evidence produced by charities; and
- the availability and quality of third-party research (e.g., academic literature) relating to mental health charity sector interventions.

Definition of evidence

Giving Evidence is aware that the term 'evidence' means different things to different people. The Oxford English Dictionary defines 'evidence' as: "The available body of facts or information indicating whether a belief or proposition is true or valid" which is obviously broad and inclusive. The types of evidence useful for decisions and evidence-based management have been categorised as per Figure 2. We found instances of evidence of each category being produced by charities we interviewed.

Figure 2: The four elements of evidence-based management
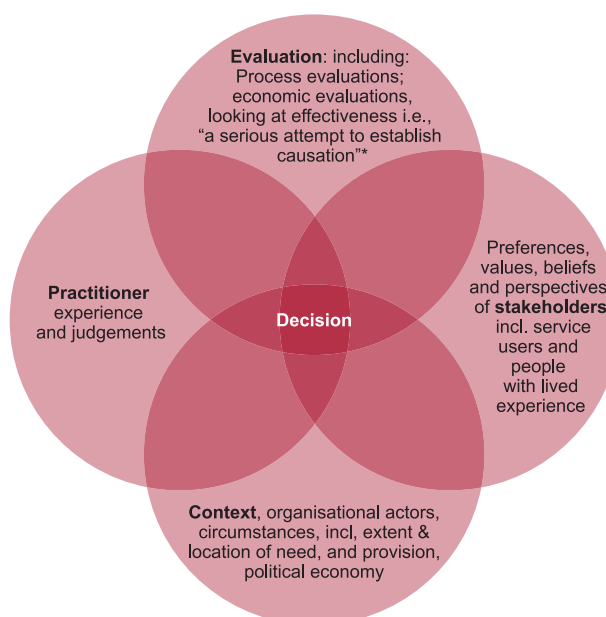
Source: mildly adapted from Professor Rob Briner, Centre for Evidence-based Management
*From Michael Kells, UK National Audit Office[iv]

- Evaluation evidence may include but is different to the inputs, outputs and outcome research that is common within the sector.
- Stakeholder evidence includes the user feedback and user satisfaction surveys that are common within the sector.
- Contextual evidence includes much of the important qualitative research conducted by the sector.
- Practitioner evidence includes charities' own in-depth understanding of the effectiveness of their work. There may be formal processes within charities to obtain this practitioner evidence.

An important point here is that an evidence-informed decision uses all these categories of evidence: they are each necessary but none is individually sufficient. Each helps to answer different questions:

- Some are better suited for **demonstrating** a (probable) causal relationship
- Others are more appropriate for **explaining** such causal relationships
- Some designs are more useful for **describing** political, social and environmental contexts[v].

An example of how these categories of evidence work together is working with people with lived experience to identify unmet needs, and then doing rigorous evaluations to ascertain what interventions are most effective in serving them; it is no use having rigorous evaluations of interventions to solve a problem which nobody has got, nor optimal to have evidence-based interventions to solve problems which stakeholders do not see as priority. Equally, understanding the context is important, as Howard White, Director of the Campbell Collaboration, explains[vi]: 'you don't need a randomized controlled trial to tell you the effect of opening the clinic another day a week if the boat only goes to the clinic one day a week'.

Various organisations have laid out *hierarchies of evidence*: these rank various research methods in terms of their openness to biases, i.e., systematic errors. The highest-ranked research methods are least prone to biases and therefore results from them are more likely to be accurate. Biases can affect any type of evidence – any of the four categories in Figure 2 above. However, the most well-known hierarchies of evidence refer only to evaluations, i.e., to the ability of evaluations to establish causation between interventions and effects. The standard hierarchy of evidence is shown below in Figure 3. Note that NICE (the UK National Institute for Health and Care Excellence) has reportedly dropped its hierarchy of evidence.

Figure 3: Hierarchy of Evidence in Evidence-Based Medicine
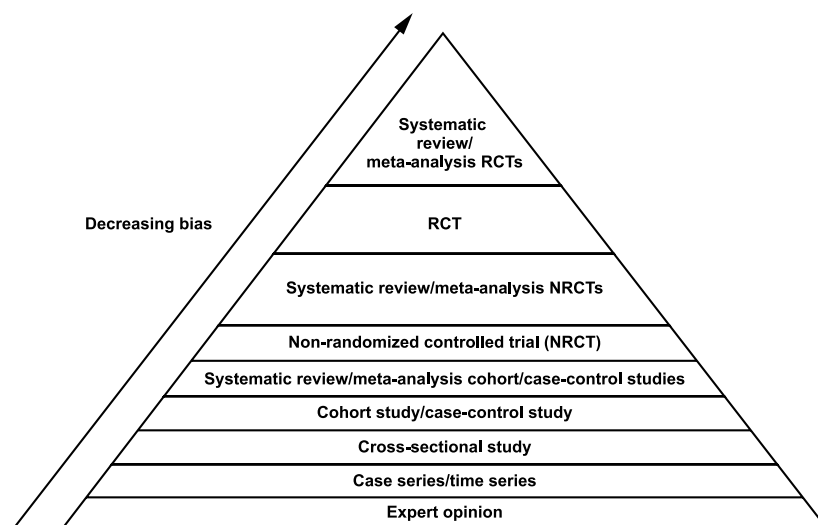
In the mental health sector, there has been – and continues to be – a sense that evidence (perspectives and feedback) from people with lived experience is inferior to 'scientific' (evaluation) evidence, and a struggle to get it recognised as valid and valuable. We hope that these diagrams and discussion show that Giving Evidence's view is that they are both necessary – and that neither is sufficient.

Indeed, the original definition of evidence-based medicine (EBM) shown in Figure 4 below from David Sackett in the 1970s highlighted the equal importance of patients values and preferences, clinical judgement and scientific evidence[vii]. **Giving Evidence believes something similar for the charity sector: practitioner judgement and feedback; user feedback and scientific evidence (for example causal evaluation research) are all relevant to designing and delivering services in mental health.**

Figure 4: What is Evidence-Based Medicine?
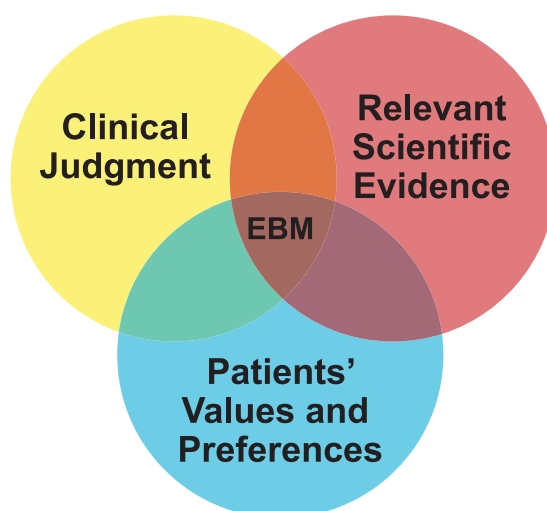
Section 1: Background about the UK mental health charity sector

Giving Evidence's findings about the evidence system need to be framed by some background and contextual factors outlined below.

The main content for this section has been drawn from a few key reports on the mental health charity sector: NPC's report on adults with mental health problems[viii] and MQ: Transforming Mental Health's report on UK mental health research funding.[ix] In this section we also include relevant information from discussions with charities and in particular with experts.

1.1. The role of mental health charities within the mental health landscape

Mental illness is one of the most common health problems: **One in four adults experiences a mental illness in any one year** - an estimated 14.7 million people.[x]

Mental health charities are relatively small in the context of the government's overall spend on mental health - NHS spending in England on mental health was £11.5bn in England in 2012/2013. Charities specialising in mental health received a combined income of nearly £500m pa, 68% of which came from the state.[xi]

However, charities play a crucial role helping / supporting people with mental health problems, for example:

- Supporting people who have not yet reached the threshold for clinical interventions and working to prevent those who are affected by lower severity mental health problems from getting worse;
- Working with statutory mental health services to improve service delivery for people affected by mental health difficulties (primary care e.g., GP practices; community care e.g., community mental health teams; and in-patient care e.g., hospitals) by providing services directly, campaigning for improved services and ensuring that the service user's voice is heard within policy debates;
- Focusing on the psychosocial aspects of mental health improvement which are crucial in helping people with mental health problems recover and which the state does not tend to prioritise. These include reducing stigma and discrimination; improving their housing; reducing isolation; supporting their family and carers; and providing education, employment or training opportunities.

Mental health charities services are complementary to those provided by statutory services. Whilst the state focuses more on medical solutions for people with mental illness and invests most of its resources in the more severe end of the spectrum of mental health problems, mental health charities tend to provide non-medical interventions and deal with the entire spectrum of mental health (including wellbeing) and emphasise prevention.

Mental health charities' services include:

- Staffed and independent housing
- Day centres
- Activities to reduce isolation and promote recovery including befriending services, hospital visiting services, mentoring and peer support groups (online and offline)
- Psychological therapies
- Non-psychological therapies such as exercise, gardening, and arts therapy
- Helplines and on-line information
- Employment training and advice
- Educational opportunities such as specialised recovery colleges providing educational courses and workshops
- Crisis services.

Charities also provide services directed at specific groups such as prisoners, ex-prisoners, mothers / pregnant women and family / carers of mental health beneficiaries.

Recovery is a key movement within the mental health voluntary sector, which has also begun to influence the statutory sector. **Recovery is about living well with a condition, rather than necessarily eliminating its symptoms.** As described by the Mental Health Foundation, the recovery model 'aims to help people with mental health problems to look beyond mere survival and existence. It encourages them to move forward, set new goals and do things and develop relationships that give their lives meaning. Recovery emphasises that, while people may not have full control over their symptoms, they can have full control over their lives. Recovery is not about 'getting rid' of problems. It is about seeing beyond a person's mental health problems, recognising and fostering their abilities, interests and dreams.'[xii]

1.2. Mental health funding

General mental health funding

Mental health is severely underfunded by both statutory and private sources. As per the graph in Box 1 on pg.7, mental health problems account for 23% of the burden of disease in the UK[xiii], but spending on mental health services consumes only 13% of the NHS budget.[xiv] During the last Parliament, funding for mental health services were cut, in real terms, by 8.25% - almost £600 million.[xv] People with mental health problems get much less charitable funding each than various other types of charitable beneficiary:[xvi]

The government appears to be recognising the inadequacy of mental health funding after much campaigning by the mental health sector. In 2015 it committed an additional £1.4 billion over five years for children and young people's mental health. More recently, in response to the report, 'The Five Year Forward View for Mental Health' by the independent mental health taskforce to the NHS in England, the government committed an additional £1 billion a year for mental health.[xvii]

In addition, Public Health England recently announced that the mental health spend by public health teams in local health authorities will now be accounted for separately, whereas beforehand it was part of a miscellaneous category (and thus lumped together with other non mental health spend). By making local public health spend more transparent, this may drive up local public health funding on mental health issues.[xviii]

Mental health research funding

Funding for mental health research is also inadequate. The UK spends £115m per year on mental health research - approximately £9.75 per person affected. This is only 5.5% of the UK's health research budget and less than 1% of what the government spends on cancer research.[xix]

Moreover, there is minimal spend on evaluating interventions. As shown below, research evaluating existing treatments and therapeutic interventions (excluding that done by service delivery charities) amounts to only £14.5m per year.[xx] This figure includes public funding as well as that of the Wellcome Trust which is an independent global charitable foundation. The vast majority of funding for mental health research aims at understanding the biological, psychological and socioeconomic processes and the risk or cause and development of ill health. Psychological therapies recommended by NICE[5] received an average of only 11.3% of mental health research spend, despite being recommended as effective for many disorders. More research is needed to understand how psychological treatments can prevent mental health conditions and promote good mental health, and to assess new treatments.[xxi]

Figure 5: Average yearly spend by research activity between 2008-2013 (£m)[6]
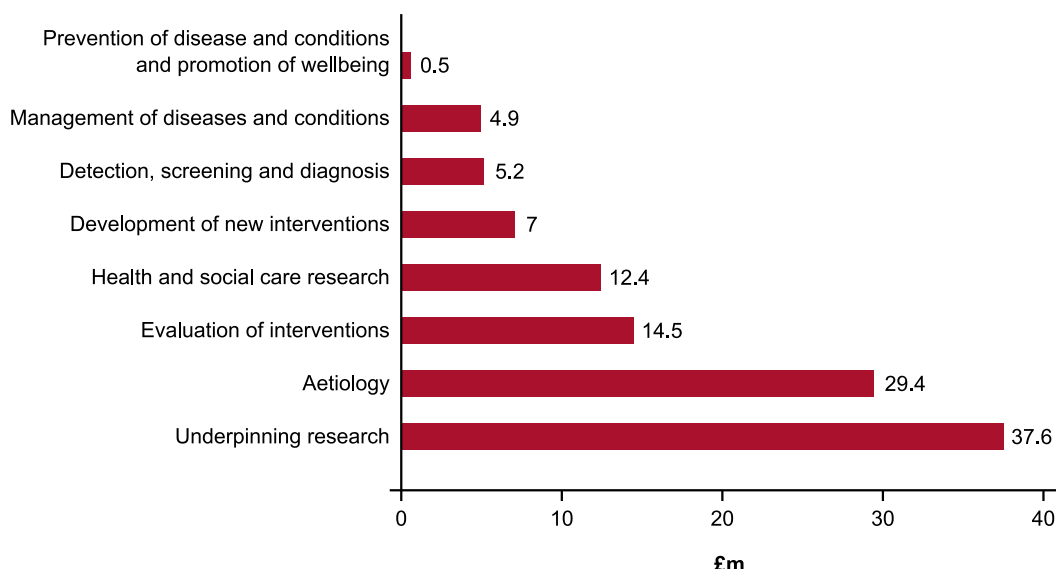
One of the major causes of this low mental health research spend is that charitable funding of mental health research is so minimal. For every £1 the government spends on cancer research, the UK general public spends £2.75. For mental health research the figure is 0.3p.[xxii]

The scarcity of mental health research funding clearly limits the effectiveness of the evidence for mental health charities.

The government has committed to improving mental health research. The government recently

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5 NICE (National Institute for Health and Care Excellence) aims to improve outcomes for people using the NHS and other public health and social care services by: producing evidence based guidance and advice for health, public health and social care practitioners; developing quality standards and performance metrics for those providing and commissioning health, public health and social care services; and providing a range of informational services for commissioners, practitioners and managers across the spectrum of health and social care.
6 Includes MH research funding from the following bodies: National Institute for Health Research (NIHR); Medical Research Council (MRC); Arts and Humanities Research Council (AHRC); Biotechnology and Biological Sciences Research Council (BBSRC); Economic and Social Research Council (ESRC); Engineering and Physical Sciences Research (EPSRC); Technology Strategy Board (TSB); Chief Scientists Office (CSO); Public Health Agency Health and Social Care (PHA HSC); National Institute for Social Care and Health Research (NISCHR); The Wellcome Trust (WT).

accepted a recommendation of the independent mental health taskforce to the NHS in England that, 'The UK should aspire to be a world leader in the development and application of new mental health research. The Department of Health, working with all relevant parts of government, the NHS ALBs [arms-length bodies], research charities, independent experts, industry and experts-by-experience, should publish a report one year from now setting out a 10-year strategy for mental health research. This should include a co-ordinated plan for strengthening and developing the research pipeline on identified priorities, and promoting implementation of research evidence.'[xxiii]

1.3. Mental health evidence base

Some experts and many charity interviewees pointed to significant weaknesses in the mental health evidence base, particularly evidence around the effectiveness of interventions and services. For example, we heard that:

- Compared to other illnesses, for example stroke or cancer, relatively little appears to be known about how to prevent, diagnose and treat mental illness

  'The causes of mental illness are still unknown – our understanding hasn't advanced like other health fields.' Charity interviewee

  'There is DSM chaos: [refers to Diagnostic and Statistical Manual of Mental Disorders] *diagnoses change over time, recommended treatments change over time, and can both depend on who is in the room.'* Expert Interviewee

- Funds spent researching treatments and interventions are mainly focused on medication and psychological therapies. There is perceived to be a lack of robust evaluation for sub-clinical services i.e., services for people with mental health conditions which are not (yet) severe enough to warrant clinical attention.

- Mental health conditions are difficult to measure which makes investigating the effectiveness of interventions hard:

  - mental health outcomes tend to be subjective (unlike, say, whether a person has a bone fracture or tumour) and hence diagnoses of them are more susceptible to bias / inaccuracy than are outcomes for non-mental conditions;

  - As a result, some people argue that mental health conditions are not well-defined.

However, other interviewees were of the opinion that there was a significant amount of evidence that could be used by mental health charities.

  'When you take any part of mental health, there is enough [research] out there for practitioners to start using.' Expert interviewee

  'A great deal is known about how to prevent, diagnose and treat mental illness, and there is a substantial evidence base for it both at a UK wide level, a European wide level and at a worldwide level.' Charity interviewee

One interviewee was concerned that by labeling the mental health evidence base as weak, the broad mental health field runs the risk of creating practitioner inaction and confusion.

'Let us look at this weak evidence. Why is it weak? What can be done about it? We nonetheless need to do something for the person in front of us. We need to move away from a nihilistic and ideological debate about evidence.' Expert interviewee

In addition, this expert interviewee felt that whilst diagnoses are artificial, heterogeneous and limited in describing individual cases, this should not be an obstacle to producing evidence, since diagnoses are useful and necessary.

'Diagnostic categories provide an essential language for practitioners. When a clinician writes a letter to a GP about a patient, he/she needs to add a diagnosis, because otherwise the GP will.' Expert interviewee

Some charity interviewees suggested that evaluation evidence pertaining to the recovery model as championed by the voluntary sector is particularly limited. This may be explained by the lack of standardised outcome measurement framework for recovery. There are some initiatives to track recovery, for example the mental health recovery star[5] shown below, but expert interviewees argue that this is not an outcome measure but rather a goal-planning tool.

Figure 6: Mental Health Recovery Star
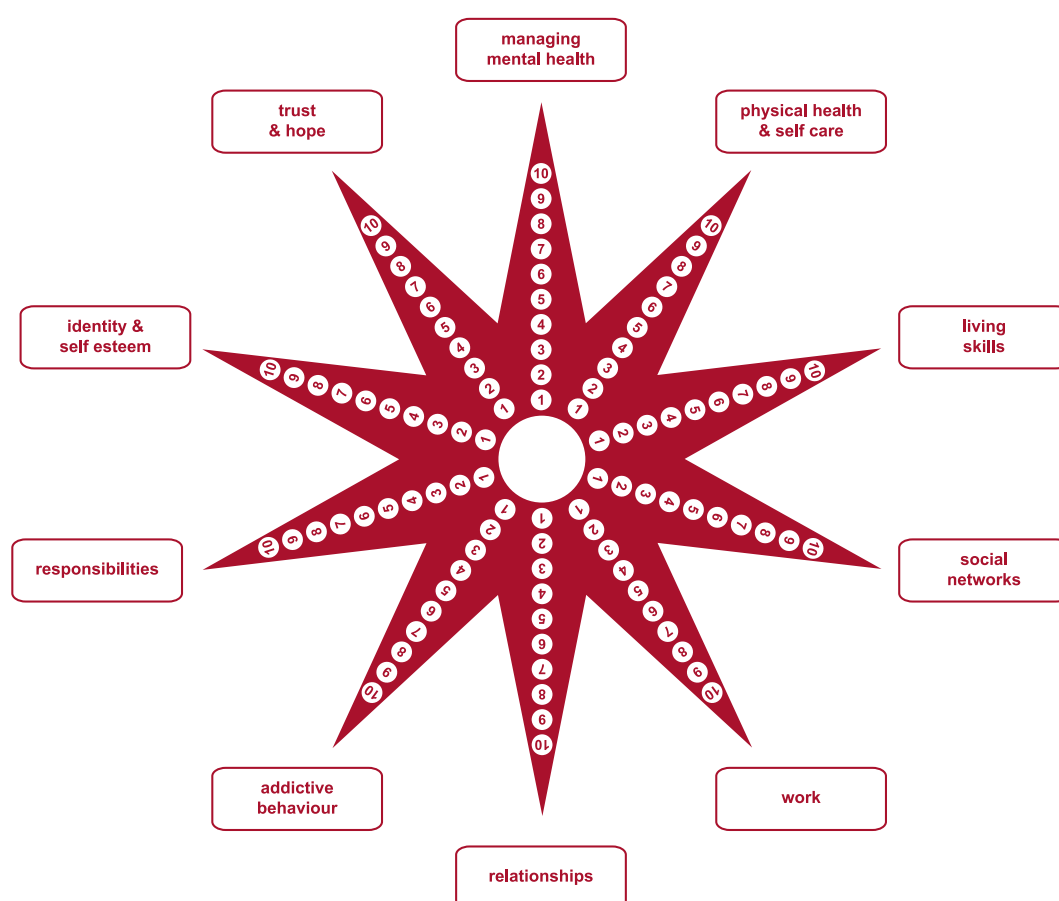
5 The mental health recovery star is designed for adults managing their mental health and recovering from mental illness. The Mental Health Recovery Star covers ten key areas: Managing mental health; Physical health and self care; Living skills; Social networks; Work; Relationships; Addictive Behaviour; Responsibilities; Identity and self-esteem; and Trust and hope. The Star Chart is co-developed by the service user and the service provider / staff member in partnerships. In some regions, such as Manchester, the Outcomes Star is being used as a commissioning tool.

1.4. Mental health charities and their understanding of evidence

We heard from many mental health charities that they consider stakeholder evidence as the most important type of evidence:

> *'Evidence for us is what our users say works: that is enough evidence for us.'* Charity interviewee

A few interviewees discussed how the term evidence itself is contested, with some feeling that the discourse needs to be reframed away from the medicalised paradigm:

> *'The challenge is how much you can generalise about human behaviour, especially if you believe in a person-centred, recovery-focused approach where you have to recognise each individual's unique life. Psychiatry and medication have a role, but should not be the dominant discourse. The focus is shifting much more away from a medical idea of health and illness towards a more social and community perspective.'* Charity interviewee

Some mental health charities had concerns about how difficult it is for anyone working in mental health to adequately diagnose and measure the multi-faceted and complex issues of mental health (and thus create a more rigorous evidence base).

However, various factors are drawing some mental health charities towards more scientific evaluation:

- A substantial proportion of mental health charity revenue comes from the NHS

  > *'As our contracts are less from local authorities and more from Clinical Commissioning Groups (CCGs)[6] where health and social care are coming together, we need to up our game in terms of proving that what we do works, particularly in relation to specific health problems.'* Charity interviewee

- Many people working in the mental health sector come from a health background and are familiar with standards / features of clinical evidence, e.g., what scientific evidence is and the types of research methods used to produce it

  > *'I am an occupational therapist by training and have come from the NHS so an interest in evidence has been embedded within me and brought with me'.* Charity interviewee

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6 Clinical Commissioning Groups are NHS organisations set up by the Health and Social Care Act 2012 to organise the delivery of NHS services in England. They consist of groups of General Practices that plan and design local health services in England by commissioning or buying health and care services.

Section 2: Key findings

This section summarises key findings about the evidence system in the mental health charity sector, as Giving Evidence understands it based on our interviews with mental health charities and experts.

It is organised according to the four parts of the evidence system:

- *Production*: mental health charities' general approach to producing evidence; the type, quantity and quality of evidence produced; how production of research happens, by whom, and how it is funded; why those people produce it; and key barriers and opportunities to improving its production.
- *Synthesis*: how the evidence produced by charities or others is synthesised and by whom.
- *Dissemination:* how evidence produced by charities is disseminated to others (outbound from the charity), and how external / third-party evidence reaches mental health charities (inbound to the charity).
- *Use:* how, why, whether and when mental health charities use evidence; what evidence they use; and key barriers and opportunities to improving its use.

In this section, there are examples of good work that many mental health charities are doing around evidence. However, these examples should not detract from the report's conclusion that there are major gaps and inadequacies in the evidence system used by mental health charities.

2.1. Production of evidence

Evidence relevant to mental health charities is produced by: academics, policymakers / government, mental health think-tanks and research organisations (which may also be charities), the private sector and service delivery charities. Giving Evidence focused on discussing with service delivery charities what they produce rather than what is produced by others. Understanding what is produced by other players is important for a thorough understanding of the evidence system as it affects mental health charities, but was not within the scope of this project.

2.1.1. Mental health charities' approach to producing evidence and its evolution

Most mental health charities spoke about a trend to understand the impact of their organisations. Charities tend to describe their involvement with evidence as a 'journey':

> *'In the last few years, we have attempted to be more rigorous about evaluating our services.'* Charity interviewee

> *'The concept of evaluation is just everywhere now: there are a lot more tools and a lot more discussions.'* Charity interviewee

Mind has been leading the field by prioritising the development of a strong evidence base for its services. It could provide an important, positive role model for the sector. Its research and evaluation activity has increased markedly in recent years. It is currently working with around 15 external research partners to deliver over £1 million of research and evaluation projects (almost £2 million including the Time to Change project[7]), and also delivers smaller scale projects in-house.

In charities that have a strong specialisation or focus on policy / campaigning, such as Mind in the UK and Hafal in Wales, there has been a greater emphasis on both producing evidence and using external evidence.

But the importance of producing evidence is also felt by service delivery charities without campaigning / research arms. For example, the Richmond Fellowship (RF), one of the largest voluntary sector providers of mental health support, has recently started to commission impact evaluations to better understand its service models. RF's motivation to create a research agenda comes from a strong focus on service quality improvement as well as a desire to influence the mental health sector through having excellent service models. Since 2012, it has published an annual listening and learning user satisfaction survey, with 1600 service users taking part in 2015. In the last year it has commissioned three impact evaluations to better understand its employment services and crisis services. One of these studies included RF, the University of Brighton and NHS England.

Yet, despite a general trend towards more emphasis on evidence, several interviewees are frustrated with how hard it is to embed an evaluation/evidence culture internally:

> *'Sometimes fundraising staff will put a budget for an evaluation of their project without consulting the research and evaluation team. We are trying to create discipline and consistency around the scoping and commissioning of evaluations as well as the use of evidence, but this is a culture change issue.'* Charity interviewee

> '*We tried to put an outcomes framework in place in the organisation and to move from a 'what we do' to a 'what we achieve' mentality. The outcomes mentality did not successfully embed in the organisation. The moral of the story is that culture eats strategy for breakfast.*' Charity interviewee

2.1.2. Specific role of mental health charities versus other players in the production of evidence

We heard from mental health charities that they are championing specific ways to improve the evidence base around mental health interventions, working with service users, academics and the government sector:

- Ensuring the service user voice is heard and heeded;
- Ensuring that research prioritises issues which service users feel is most important;
- Ensuring that research is practical and service-user orientated. Mental health charities are bridges between academics and their service users, communicating any interesting new research to users via newsletters, helping with recruitment for research projects and ensuring that users are treated ethically;
- Commissioning / conducting research in important areas which are less prioritised by medical research e.g., prevention and wellbeing.

**7** Time to Change is a campaign to end the stigma and discrimination that people with mental health problems face in England and Wales. In England, it was formed in 2009 with funding from the Department of Health, Comic Relief and the Big Lottery Fund. In Wales, the campaign was launched in 2012 under the name Time to Change Wales, led by Welsh mental health charities Mind Cymru, Gofal and Hafal

An example of a charity actively involving users in prioritising research is Welsh mental health charity, Hafal. In 2013, it ran a one-day workshop with service users and carers to prioritise mental health research topics. There were six workstations with an 'expert' and a scribe and users had the opportunity to discuss and contribute to the topic at each workshop. 103 research ideas were generated which were sent to the Mental Health Research Network and various academic leads. The initiative identified gaps in research, for example how to make education the centre of the recovery process. More recently, Hafal issued a newsletter dedicated to outlining the latest mental health research sent to all of its members (currently over 1,500).

2.1.3. Type, quantity and quality of evidence produced by mental health charities

Substantial evidence about context and stakeholders has been produced by mental health charities. However, until recently, there were few rigorous impact evaluations produced by charities (i.e., investigating causation), with the consequence that many services may not be based on robust scientific evidence of effectiveness. In the last few years, charities have started to produce more evaluation evidence.

Figure 7: Percentage of charities interviewed who said that they produce evidence of various types
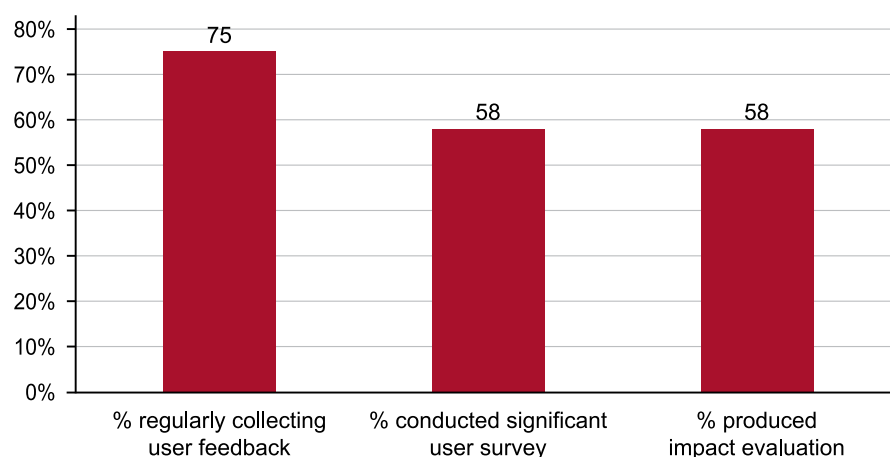
Note: n=12 charities

Source: charity interviews and secondary research

Practitioner evidence

We heard from a few charities that there are formal processes to incorporate feedback from staff on the effectiveness of different services. For example, the Richmond Fellowship has a performance, quality and innovation team which has 8-9 people providing internal monitoring / continuous improvement work.

Contextual Evidence

There has been some psychosocial qualitative or mixed-methods research by charities which is mostly focused on understanding mental health beneficiaries more deeply (aetiology and underpinning research). This is where historically most research spend by charities has gone rather than, for example, on impact evaluation.

An example is SANE's research on suicide and self-harm. From 2009-2013, SANE carried out

two major studies exploring the insights of people who have experienced suicidal feelings, have attempted suicide or have been close to someone who has attempted suicide. The first, 'The Experience of Suicidal Feelings' was based on data gathered from 120 people using interviews and questionnaires, asking what it is like to feel suicidal. The second, 'A New Focus for Suicide Prevention' interviewed around 45 people. In addition, SANE conducted a major qualitative research study on self-harm. It collected data via an online survey from 946 anonymous people aged 12 to 59. The data show self-harm behaviour from first episodes through to full recovery.

Stakeholder evidence

Of the service delivery charities interviewed, 75% regularly obtain user feedback about their services and 60% had conducted a significant user survey detailing user-rated impact of their services.

> *'We can't know how we are doing from Head Office. We need to ask users what works well and what doesn't',* Charity interviewee

Data monitoring

Many interviewees consider data about inputs and outputs as important evidence about their effectiveness (though those data alone don't establish causation). Below is what we heard from charities about inputs, outputs and outcome measurement.

All charities interviewed reported regularly monitoring the number of referrals, number and types of service users (demographics, diagnosis) etc.

Charities increasingly routinely monitor outcomes for their beneficiaries, with nearly all charities interviewed measuring outcomes for some services and a significant proportion collecting progress data on every service or user.

- Measuring clinical progress and wellbeing outcomes:
    - Several standard clinical tools are used by mental health charities, primarily due to commissioners' requirements: PHQ9 to measure the incidence of depression; GAD7 to identify the presence and extent of generalised anxiety disorder; Clinical Outcomes Routine Evaluation (Core 10) to measure the intensity / severity of anxiety, depression, trauma, physical problems, functioning and risk to self; the Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS). These are all third-party self-assessment questionnaires completed at the end of every counselling session. Only a few mental health charities interviewed regularly use these tools to monitor impact.

- Measuring recovery:
    - The mental health Recovery Star was mentioned relatively frequently by interviewees (although this is more of a tracking rather than an outcome monitoring tool). Four of the charities interviewed have developed their own recovery outcome monitoring tool for service users as they preferred a more customised measurement tool.

- Measuring 'hard' outcomes:
    - Mental health charities tend to measure 'hard' outcomes for specific projects[8] depending on the project aims e.g., whether the client has maintained work; is back in work, employment or training physical health improvements (amount of

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8 Throughout the document we use the term 'project' where charities spoke about 'project', though others might say 'intervention' or 'service'. These three terms are used here interchangeably.

- physical activity, Body Mass Index (BMI), whether still smoking); number of hospital admissions; amount of visits to GPs and prescriptions
    - Some interviewees felt that there could be much more meaningful outcome-monitoring if there were better data sharing between the NHS and the charity sector.
- We heard that there was an overarching industry attempt by the Mental Health Providers Forum to create a standardised recovery outcome measurement tool for its members but this did not ultimately gain traction.

'We would really like to be able to benchmark ourselves against other organisations but the data is not available.' Charity interviewee

Recently, charities have begun to create outcomes frameworks to determine their impact as an organisation, although they have found aggregating impact difficult:

- Several charities have been working with external parties such as the Charities Evaluation Services to develop theory of change models which have specific measurable outcomes;

- Other charities are moving towards implementing overall outcomes frameworks, monitoring a few key outcome measures.

'It is a real challenge to have a consistent measurement approach across the organisation and common goals' Charity interviewee

'Every contract specifies different outcomes, which makes it a nightmare to aggregate' Charity interviewee

Some interviewees mentioned that their charity collects significant amounts of input, output and outcome data but they are not fully analysed, thus an opportunity is missed (mostly due to resource constraints) to generate meaningful insights about the interventions.

Evaluation evidence
Charities have historically done few impact evaluations, although this is changing and the number and sophistication of impact evaluations is on the rise. Over 50% of charities interviewed had produced one or more impact evaluation over the last five years, with the vast majority completed in the last year.

An example of a charity committed to an evaluation research agenda is Family Action which has conducted / commissioned evaluation research on most of its services. In 2014 it published an impact report looking into evidence relating to a programme / service in each of its key areas, including a randomised controlled trial, independent evaluation and economic evaluation of its perinatal support service; an external cost-benefit and internal analysis of its family support services; and an independent evaluation and cost-benefit analysis of its WellFamily services.

However, most evaluations are done on very small budgets, which inevitably constrain their rigour, reliability, and usefulness. Evaluations completed have tended to be small-scale, mostly costing between £5-£10k, although a few have been in the £20-£30k range.

Large-scale impact evaluations establishing causation are relatively unusual but growing. Mind is an example of a mental health charity driving best practice in the sector by obtaining funding and commissioning such evaluations. An example is the Time to Change campaign evaluation. Mind and Rethink (partners in Time to Change) have worked closely with the Institute of Psychiatry, Psychology

and Neuroscience at King's College London, as well as other research partners, to establish causal links between their anti-stigma interventions and population level changes in knowledge, attitudes, and behaviours. This work is recognised internationally as leading work to understand mental health stigma.

Mental health charities have used and experimented with various methods in impact evaluations. There are examples of economic evaluations, including Social Return on Investment (SROI)[9] and cost-benefit methods. The majority of impact evaluations use pre-and post-outcome measures supported by some qualitative interviewing.

Although not within the scope of the project, Giving Evidence is interested in the quality of evaluations produced by mental health charities and noticed that:

- The majority of impact evaluations produced by the mental health charities interviewed do not investigate causation. They mainly compare measures (e.g., a person's well-being) before versus after the intervention. This method can be cheap and easy, but is very open to bias and conclusions about causation can be highly misleading (because the cause of any change is unclear);
- The impact evaluations often had small sample sizes. This again can lead to the conclusions being inaccurate (see Appendix 3).

2.1.4. Funding the production of evidence by mental health charities

Historically research and evaluation spend used to produce evidence has been minimal compared to overall charity spend. Budgets for evaluations were tiny e.g., the evaluation of Mind's programme Ecominds was done on an £8,000 budget against a programme budget of £3.5 million. Mental health charities interviewed that have been successful in obtaining evaluation budgets from CCGs / local authorities have only secured very small amounts of funding. **Interviewees are frustrated by having multiple, small-scale impact evaluations attached to specific projects rather than one large sum with which to conduct a more meaningful and large scale piece of evaluation research.** This situation arises due to evaluation funding from external sources (primarily CCGs) being attached to specific projects.

In the last few years, more funds are being dedicated to research and evaluation, and thus to the production of evidence, particularly in the larger charities. For example:

- Mind has recently asked for 10% of the budget of large contracts for research and evaluation. The Blue Light programme, which provides support for the mental health of emergency service workers, has an evaluation budget of over £400,000 - including an RCT with the University of Oxford. Mind's research and evaluation projects also include studying the impact of peer support (£350,000) and the role of sports participation in mental health recovery (£95,000).
- The Time to Change campaign in England run by Rethink and Mind has a budget of over £1 million for evaluation and research.

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9 SROI is an analytic tool for measuring and accounting for a much broader concept of value, taking into account social, economic and environmental factors. SROI measures change in ways that are relevant to the people or organisations that experience or contribute to it. It shows how change is being created by measuring social, environmental and economic outcomes and using monetary values to represent them. This enables a ratio of benefits to costs to be calculated. For example, a ratio of 3:1 indicates that an investment of £1 delivers £3 of social value.

Evaluation research done by the mental health charities interviewed has primarily been funded by external parties either by CCGs or large-scale funders interested in evaluation such as the Big Lottery Fund and Comic Relief.

We heard that funding the production of evidence is a particular challenge for small and medium-sized charities. Smaller service delivery charities mentioned cutbacks from local and central government affect their ability to monitor or evaluate as they are being forced to keep costs down.

> *'With a small staff and a range of activities, things like training and research are ones that are harder to sustain'* Charity interviewee

2.1.5. Who produces the evidence funded by mental health charities?
Mental health charities are increasingly outsourcing impact evaluations to specialist mental health researchers / providers. Indeed, there is a growing evaluation industry. Most recent impact evaluations of mental health charities interviewed were produced by external consultants or academics. Interviewees in general seemed happy with their experience of working with external evaluators and believed that external evaluations were useful because they had a greater influence on commissioners and clients who respond differently to external evaluators. Interviewees felt that external specialists have skills and resources which they don't.

Increasingly large charities are commissioning research and evaluation rather than completing it internally, which means that they are reducing internal research teams. Charities well known for their research such as SANE and Rethink are paring down their internal teams. It is Giving Evidence's perspective that this may diminish internal cross-pollination between research and service delivery as there will not be distinct teams exchanging ideas and insights. However, external agencies bring more independence as well as new and fresh dimension to the mental health charity research sector.

The evolving pattern among mental health charities seems to be that research is increasingly collaborative rather than being owned by one charity and is being implemented by external agencies, primarily universities: for example, Mind has over fifteen evaluation partners including many universities; Thrive has worked closely with the Centre for Child and Family Research at Loughborough University and has co-produced several important publications; and the Richmond Fellowship is involved in a study with the University of Birmingham and Birmingham City University.

An example of an exciting, collaborative large-scale evaluation is the peer support project evaluation. Big Lottery Fund has provided £3.5 million to Mind, Bipolar UK and Depression Alliance to develop a programme to raise awareness of, and deliver, mental health peer support across nine regions of England and their online peer support platform, Elefriends. There has been £320,000 set aside for evaluation by the McPin Foundation, St George's, University of London Social and Mental Health Community Health Research Institute and London School of Economics.

Whilst some charities have academics or highly-skilled researchers in-house and are producing high quality evidence themselves, we heard from many charities, including smaller ones, that they are increasingly keen to collaborate with academics and universities on research and evaluation.

> *'We have recently been introduced to academics with the knowledge, discipline and skills to conduct research in a way that is more than half-baked.'* Charity interviewee

Indeed, there is fertile ground for a very strong collaborative relationship between academics and charities. Academics can help to improve the quality of the research produced by charities, such that it can make a real contribution to the mental health evidence base[10]. Specifically, academics can help charities to organise and describe their data i.e., to improve the quality of reporting and make it understandable.

> *'There are very interesting data-sets sitting inside charities.'* Expert interviewee

In addition, observational studies, with pre and post outcome measures that charities are currently producing, could be more valuable to the wider mental health research and practitioner community if they are produced in a more scientific manner i.e., with research protocols and peer-review.

> *'Academics can work with charities to ensure that their research is methodologically sound.'* Expert interviewee

Academics we spoke to emphasised how important charities are for their work, as they are close to and can act as a bridge to the people with mental health problems, their family and carers. They also offer a 'different angle' than the clinical perspective.

Yet, we heard that there could also be difficulties working with academics. Interviewees mentioned that it is hard to get academics to do full-scale proper research because the funding process is slow and the service may not exist in the same form by the time the funding comes through. In addition, one expert mentioned that some charities could be 'bullied' by academics who for example 'run off with the data' or fight over authorship of journal papers. One charity mentioned that it would be good to have more funding for research where charities were the lead investigators rather than the current situation where charities have a lesser role to play in most of these partnerships.

2.1.6. Motivation for producing evidence

All charities mentioned funders as either a strong or fairly strong reason for producing evidence. This is consistent with the voluntary sector as a whole, as detailed in Appendix 4.

According to interviewees, the importance of evidence to statutory bodies is varied:

- Health commissioners are perceived to be more outcomes-driven than local authority bodies, although one interviewee felt that the NHS is quite lightweight in terms of evaluation criteria and does not actively audit outcome data submitted;
- Impact evaluations are often conducted for marketing to commissioners or to secure further funding for a project continuation or roll-out;
- There are cases of organisations being funded by local authorities where no outcome data have been sought and others where it was perceived that a disproportionate amount of time / resources was spent collecting outcome data.

One interviewee felt that until commissioners start to really value and place weight on evidence, charities will continue to find it hard to justify prioritising spend in this area, in the light of cuts and a challenging funding environment.

> *'Although evaluations / evidence are talked about a lot, when it comes down to it, commissioners pay lip service towards it.'* Charity interviewee

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10 The UK Economic and Social Research Council ran a funding programme in 2014 on almost exactly this: for academics and charities to partner to organise and make available the useful data held by charities.

Several charities mentioned that the Big Lottery Fund and Comic Relief are important players in funding and prioritising an evaluation agenda.

> *'The Big Lottery really cares about evaluation – it actually expects you to evidence your work unlike other funders.'* Charity interviewee

Many mental health charities stated that it was the internal drive to understand impact that was the primary reason for producing evidence. Indeed, various interviewees mentioned that they went beyond what was required by funders in terms of evidence (and often had to pay for this from their own resources since they could not get funding for it).

> *'We wanted to have an outcomes programme for our own self-worth. We needed to show we were in the 21st Century.'* Charity interviewee

> *'We aspire to become a better player, fully armed with evidence.'* Charity interviewee

> *'We are confident that the services we provide are good, but we do want to hear about any problems.'* Charity interviewee

2.1.7. Barriers to the production of evidence by mental health charities

We heard from many charities that they are struggling with outcome monitoring. There is some recognition that outcome measurement tools are weak (although a few interviewees felt that this was an excuse used by the sector not to do proper monitoring / evaluation).

> *'It is hard to objectively assess whether people are getting better and hence compare interventions.'* Charity interviewee

> *'In mental health there are so many different factors that can influence the definition and outcomes around mental health. To identify outcomes for individual service users is almost impossible since each individual's problems is so varied.'* Charity interviewee

Funding and resourcing appeared to be major barriers, particularly for small and medium-sized charities. Mental health charities said that that they would like to produce more high-quality, rigorous evidence but they don't have the budget for it.

> *'Proper research is expensive and we are facing intense financial pressure with the cutbacks in central and local government.'* Charity interviewee

> *'We conducted this evaluation on a shoestring. We are very happy with it and we don't worry about its robustness, but imagine if you had specialists and resources.'* Charity interviewee

2.1.8. Opportunities in the production of evidence by mental health charities

There are some moves to increase funding and rigour within mental health research. For instance, researchers in the McPin Foundation put their research plans through ethics committees and strive to publish in peer-reviewed journals.

Box 2: About The McPin Foundation

The McPin Foundation is a mental health research charity that involves and champions experts by experience in research. They deliver high quality user-focused mental health research, and provide expertise to others in how to effectively involve people with mental health problems in research not as participants but as collaborators, advisors, and peer researchers. The model is built on principles of collaboration so they work in partnership with a range of organisations across acadmic, public and voluntary sectors.

For example, in 2014/5 it partnered or was commissioned by six public sector organisations, nine voluntary sector organisations and 20 academic partners[xxiv]. The McPin Foundation works to bring the different worlds of academia and charities together, serving as a bridge between the two. A good example of this is the Partners2Study which illustrates their unique role within the mental health research landscape. This study aims to develop better ways for primary and secondary services to collaborate in order to support people with severe mental illness. The research programme involves the universities of Bangor, Birmingham, Exeter, Lancaster, the London School of Economics, Manchester, Plymouth, and Warwick.The McPin Foundation is delivering a public and patient involvement (PPI) programme for the study – collaborating with academic teams to work alongside people with lived experience to co-produce quality mental health research.

In 2014/5 the McPin Foundation published five peer-reviewed journal articles. It has established Lived Experience Advisory Panels in several parts of the UK.

There is a growing sophistication, particularly by larger charities, in commissioning external research. Some charities have commissioned or are hoping to commission systematic reviews on areas relevant to their interventions.

2.2. Synthesis of evidence

Our interviews did not dwell on synthesis. Nonetheless, we heard from some charities that they do not use NICE guidelines much because they are '*perceived to be more at the medical end of the spectrum'* (charity interviewee). In addition, '*they require a lot of poking around, and it is easier just to pick up the phone to someone you know.'* Charity interviewee

2.3. Dissemination of evidence

'Dissemination is a really difficult thing even for established academics, so imagine what it is like for charities. The challenge is how to get people to listen, when they already think they have got it right.' Charity interviewee

'The voluntary sector has a responsibility to share its work. It is important that as innovators charities, are able to evaluate, write-up and share their work.' Expert interviewee

2.3.1. Outbound from the charity

In discussing with charity interviewees the issue of dissemination, we were interested in how much of their evidence was published. We considered that if the material was technically public via websites then it was published. However, many charities understood the term 'published' to mean in journals, which few of them do.

Mental health charities publish outcome and user feedback data on their websites and/or annual / impact reports, but they do not tend to do this in full or in a clear way

- Highlights of outcome data and user satisfaction numbers are published often without detail on how these numbers were collected, the sample size, etc;
- Only one third of the charities that conducted service user satisfaction surveys had published a full report of the results.

Withholding of evaluation evidence does not seem to be an issue

- In Giving Evidence's research into the publicly available materials of mental health charities interviewed, we saw that most impact evaluations mentioned by interviewees are published on the charities' websites;
- Where impact evaluations have not been published this was:
    - For competitive reasons, particularly where mental health charities are competing for commissioners' contracts (some charities such as Mind do not have such competitive pressures and so can perhaps be more transparent):
    'We don't want competitors to pick this up.' Charity interviewee
    - Because they were perceived to have limited relevance to others
    'Our service is unique – I think that there is a limited amount that would be applicable or interesting to other parties.' Charity interviewee
    - Due to resource issues
    'We don't have the capacity. We would like to get our research into academic journals but we don't have the head space. There are so many processes and loops.' Charity interviewee

One charity interviewee mentioned that some evidence may not be published by mental health charities due to concerns about the underlying data quality.

There may not be significant demand for published evaluations or evidence by mental health charities

- Interviewees did not think that evaluations of their services had been downloaded / used much by other charities.

There are some emerging best practice examples of dissemination in the sector. For example, Mind is committed to sharing its learning with the rest of the sector. It ensures clear and detailed research reporting, and requires all researchers to publish a report and a lay summary. Academics are contractually required to publish in a peer-reviewed journal and the fee paid to academics includes the cost of making that open access. Mind requires that the full evaluation report includes: (a) the protocol; and (b) full details of all of the questions asked and analysis done. These are great safeguards against poor research practices, such as selective publication, or 'mining' data for particular results.

A few charities are successfully disseminating their evidence to inform the development of public policy. Welsh Charity Hafal told us that their evidence has been extensively used by the Welsh government to develop and implement mental health legislation in Wales and by NHS Wales to drive up standards in mental health service provision. Hafal has produced evidence relating to prudent healthcare in Wales which is a main political driver within NHS Wales. It is responsible for a dedicated 'Mental Health Wales' website and journal disseminating the latest research and news.

However, in general, there is minimal active dissemination of evaluation evidence produced by small and medium-sized mental health service delivery charities:

- Mental health service delivery charities interviewed do not tend to publish impact evaluation material in peer-reviewed journals;
- The major reason interviewees spoke about for the lack of active dissemination of impact evaluations was that they were seen primarily for internal use and they did not have the resources / time / incentive to actively disseminate. Moreover, unlike qualitative research, funders and implementers are not pushing for publication / dissemination.

There are a few examples of small charities actively disseminating via conferences. For example, Thrive organised a seminar in 2014 about 'Green Care, White Care – Gardening and Growing for Health' where it shared its research, and provided a platform for others to do the same. The audience comprised public health professionals, clinical commissioners, local authority directors of social care and GPs. Recently, Thrive has contributed to two peer-reviewed papers published in The British Journal of Occupational Therapy.

There seems to be more active and innovative dissemination of contextual evidence - this may be because it is less commercially sensitive than evaluation or stakeholder evidence. An example is SANE's research on suicide prevention. From 2009-2013, SANE carried out two major studies exploring the insights of people who have experienced suicidal feelings, have attempted suicide or have been close to someone who has attempted suicide: a) The Experience of Suicidal Feelings and b) A New Focus for Suicide Prevention. SANE on Suicide was set up to disseminate the findings. Each section of the website contains excerpts from interviews describing experiences of the process of suicide. Each experience shows the point of view of both the suicidal person and a family member or friend. There are suggestions for getting support, accounts of recovery and a space to share stories. SANE feels that by making its research dynamic and practical, it has attracted people to its site. 'There is an open information flow in and flow out and incredible material coming from service users.'

'*Technology has advanced so much in the last years: this must be key to helping with dissemination*.' Charity interviewee

2.3.2. Inbound to the charity
Many mental health charities interviewed discover external research / evidence through diverse channels, mostly informal.

- For many charities, particularly smaller ones, since reviewing academic literature is time-consuming and requires special skills, they obtain useful and timely digested evidence from academics, advisory panels or other word-of-mouth routes;

    'We have a clinical governance group who are all NHS employees and meet four times a year. They will review services and discuss any new needs and evidence.'
    Charity interviewee

- The larger charities spoke about the close relationships that they had with academics working in their field and how they have constant interactions with academics through their externally commissioned research;
- Digesting evidence relevant to their specific area of work is a key part of individuals' roles in the organisation.

Information sharing across the mental health charity sector is weak

- Interviewees did not use research from other charities – meaning that the vast majority of evaluations by charities, even if they are published, do not get used by the rest of the sector.

There is not a single 'go-to' place or repository for relevant evidence relating to charity mental health interventions. However, there are exciting new initiatives, such as the website Mental Elf, and The What Works Centre for Well-being which may increase the use of existing evidence by mental health charities:

'Mental Elf is a great resource – the way that it is written is fabulous and interprets research. That kind of engagement is good.' Charity Interviewee

Box 3: The What Works Centre for Well-Being

The What Works Centre for Well-Being is the latest addition to the 'What Works Network', launched by the Government in 2013 to improve public services through evidence-based policy and practice. Modelled on NICE, the centre is commissioning a research synthesis of what works, and secondary data analysis, initially in three areas: employment and learning; community wellbeing; and culture and sport. The centre aims to get evidence of what works to those areas and organisations that can use it to best effect. The What Works Centre for Well-Being is an independent collaborative organisation funded, financially and in kind, by over 17 partners.

Box 4: Mental Elf

The Mental Elf is a website which aims to keep a wide audience interested in mental health informed and up-to-date about recent research. Its team of mental health experts post blogs every day with short and snappy summaries that highlight evidence-based publications relevant to mental health practice in the UK and further afield. It scours over 500 sources of evidence (journals, databases, websites) to find key guidance, systematic reviews and other high quality research and reports to help make practice more evidence-based.

In addition, mental health research and policy charities such as the Centre for Mental Health (which was interviewed for this study, but considered an expert interviewee rather than part of the group of 12 service delivery charities) and the Mental Health Foundation work hard to disseminate evidence they produce and synthesise to the statutory and voluntary sector, creating the opportunity for the widespread adoption of more evidence-based approaches.

Box 5: Centre for Mental Health

Centre for Mental Health changes the lives of people with mental health problems by linking research evidence with policy and practice. It seeks evidence of the biggest inequalities facing people with mental health problems and finds and tests promising approaches to address them. It makes recommendations to policymakers (nationally and locally), commissioners and service providers about what needs to change, and it supports implementation and the scaling up of good practice across the country. The Centre was founded in 1985 and until 2010 received core funding from the Gatsby Charitable Foundation. It is now an independent charity.

Examples of where the Centre for Mental Health has impacted policy are in the field of employment of people with mental health problems. They garnered evidence from 17 international randomised controlled trials which illustrated that Individual Placement and Support (IPS) is by far the most effective approach to achieving better outcomes. The Centre worked to support the adoption of IPS across England. Beginning with one local trust in South West London, it provided information, publications, training and practical support to mental health services wishing to adopt IPS. It established a network of Centres of Excellence in IPS, each of which helps others to take up the approach, and its regional trainer programme is extending availability to areas where it has not previously been available. It is now estimated that about half of mental health trusts have some IPS services.

Moreover, the Centre for Mental Health's evidence about the value of investing in children's mental health contributed to the case for the government investing an extra £1.25 billion on it over the course of this Parliament. The Centre analysed longitudinal data from birth cohort studies to explore the prevalence of mental health problems among children and its consequences for later life. The research identified the importance of behavioural problems as predictors of very poor outcomes for children and young people and investigated which interventions are most effective and cost-effective.

2.4. Use of evidence

2.4.1. Mental health charities general approach to using evidence

Mental health charities say that they are committed to using evidence, both their own and external research. Of the mental health charities interviewed, 10 mention in their annual reports or websites that they seek to underpin their services by evidence.

> *'Right from the top, everyone sees research as an integral part of what we do. We are always looking for how we can improve how information comes in and out of the organisation.'* Charity interviewee

However, despite significant declared interest in using evidence, apart from a few of the larger charities, most charities interviewed have not yet achieved an evidence-based culture, even if it is a stated organisational aim. Evidence which they produce is more often used for funding/marketing purposes than for designing / improving services or organisational learning.

2.4.2. When and how mental health charities use evidence

Interviewees struggled to provide specific examples of how the evidence they produced had been used for learning purposes. Whilst various outcome data are collected for funder and organisational reporting purposes (using significant resources), they are rarely aggregated and analysed in a meaningful way. Few interviewees could cite examples of how impact evaluations had informed their service delivery.

However, user feedback and satisfaction surveys do seem to significantly inform service delivery. For example, Welsh mental health charity Hafal designed and implemented a new service to support its clients in their dealings with police after they heard from many users how problematic their relationship with the police could be.

For the majority of mental health charities, there appears to be little routine, conscious or formal use of third-party evidence. Use is sporadic - as and when needed, for example:

Funding/marketing purposes
- To secure funding for new activities, to prove the need for the project as well as to indicate that it will achieve good outcomes;
- External evidence is primarily sought to validate and 'prove' an idea.

Designing new services
- To develop a new programme / service, to inform its design as well as to help to fundraise for it. For example, Richmond Fellowship used external research to help it develop its crisis services since there is significant third-party research about how people with mental health problems fare in alternative settings, such as hospitals.

Developing a campaign
- Campaign / policy teams use external research to generate ideas for new campaigns and to develop policy briefs. For example, the external evidence that people with poor mental health often suffer from poor physical health as well (e.g., 65% of people with schizophrenia smoke) informed the development of Hafal's campaign around physical health.

  'Our media / campaign team is on top of any publicly discussed new piece of research pertaining to mental health.' Charity interviewee

Education/training
- Where charities are involved in the delivery of education or training pertaining to their intervention, they routinely follow the evolving evidence. For example Thrive has a role as trainer / educator in the field of social and therapeutic horticulture (STH).

There were only a few examples of routine updating / reviewing / refining of services based on new or emerging evidence. These include SANE's monthly academic journal discussion club which includes mental health practitioners and volunteers and Jami's quarterly clinical governance group containing NHS employees which discusses any new evidence affecting existing services.

2.4.3. The evidence which mental health charities use

Mental health charities are mostly using grey (i.e., non-peer-reviewed) literature which they pick up through the media and their networks. They tend to rely on charities which specialise in mental health research such as The Mental Health Foundation (described in Box 6 below) and the

Centre for Mental Health (described in Box 5 above). Smaller charities access research from larger ones such as Rethink. In addition, mental health charities access research produced by the King's Fund and statistics from Public Health England and the Office of National Statistics.

Experts suggested that charities' use of academic literature may be low because there is limited synthesis, and because much of it is based on a more medical approach to mental health rather than the recovery model to which mental health charities tend to subscribe.

Box 6: The Mental Health Foundation

Develops and runs research and delivery programmes across the UK to provide evidence and expertise about what works as well as how to intervene earlier. This research is used by MHF to influence policy and improve service delivery. MHF has been active in promoting the idea that good mental health and wellbeing is for everyone and not just those experiencing problems. It works at the forefront of mental health, often focusing on overlooked and under-researched areas such as personality disorders and mental health issues that affect black and minority ethnic people.

Mental health charities interviewed rarely use evidence produced by other charities. We heard that this was because this evidence was often hard to find, perceived to be overly positive and not properly described (i.e., interventions, populations, research method).

> *'Other charities seem to say that 'x % of our beneficiaries love us' but this is just and advert or 'our project improves outcome by y%' but this doesn't tell us how it could be done better.'* Charity interviewee

Contextual evidence, such as Sane's research on self-harm, does seem to be more widely shared and digested by the sector. For example, the Richmond Fellowship actively shared this research with its best practice group.

2.4.4. Barriers to greater use of evidence

'It is not clear that you can march the evidence out and expect it to be implemented.'
Expert interviewee

During our interviews we heard about the following barriers to the use of third-party evidence:

- Availability of useful evidence:
    - *Findability:* Interviewees mentioned that evidence is not easy to find or stored in one place;

    - *Clarity*: They also said that the information which does exist is not clear enough to be useful. For example, Hafal has looked at external evidence to help support the development of a new recovery centre. It conducted a literature review of the evidence but felt that the research did not give enough background or nitty-gritty about the types of services provided. For example, research would speak about running a 12-week programme, without saying exactly what the programme comprised;

    - *Cost*: Few small- and medium-sized charities can afford to access academic literature due to journal pay-walls (this problem is particularly acute for material which predates Open Access). We heard from interviewees, even of some larger charities, that they have to find ingenious ways to access research databases by, for example, physically going to their old universities.

- Cultural: interviewees often mentioned internal resistance to greater focus on outcomes, measurement and evidence.

- Skills / time / resources: many smaller and medium-sized charities felt that they had the skills, but not the time, to produce or commission their own research and to make best use of external research. A few acknowledged that they lacked the skills to be able to find and process third-party research. Experts commented that there may be an issue of research literacy in the mental health charity sector.

- Applicability:
    - Many interviewees considered the applicability of third-party research to their intervention as low due to the specificity and individuality of their intervention, beneficiary mix etc;

    - Academic literature pertaining to mental health interventions is not considered practical enough as well as being hard to decipher;

      'Academic research has to be re-written to make it at all intelligible.' Charity interviewee

    - Interviewees mentioned that funders tend to value third-party evidence less than that produced by the charity itself. Commissioners want evidence around specific interventions, and may not accept relevant evidence on which those interventions draw;

'Funders are asking: what difference are you making? What distinguishes you? They don't want generic evidence or information.' Charity interviewee

- Since evidence produced by charities tends to be project-specific, interviewees mentioned that when the project shuts down, its evidence stops being relevant. Funders want evidence about each specific project. Since the intervention or service delivered within each project often changes slightly, funders may discount evidence from a similar project that was evaluated in the past.

2.4.5. Opportunities for greater use of evidence

Many mental health charities, even smaller ones, appear to be plugged into networks and groups. They hear about and digest evidence through these groups.

'You learn from each other. You come together and compare notes. You become aware about bits of research.' Charity interviewee

There are good practice examples of large charities using third-party evidence which may influence the sector, such as the Samaritans (which does not consider itself a mental health charity since it provides emotional support rather than mental health services). In its annual report, the Samaritans describes how as part of its new strategy 2015-2021 it **will improve the collection and application of evidence** (one of four top priorities) so that:

- It can better demonstrate its approach to supporting people, the benefits this provides and its contribution to reducing suicide;
- It can understand the needs and profile of the different groups of people who use its services and what they get out of those services;
- It can apply existing evidence about 'what works' to improve and develop its support services;
- It can evaluate the impact of Samaritans' strategy.

The Samaritans 2015-2021 strategy document states that there is 'need for evidence to inform action. There is a large body of research about suicidal behaviour, but only limited evidence about what works best to prevent or reduce suicide, for different groups. We need to build the evidence base that will help to inform effective action to reduce distress and suicide.'[xxv]

Of the 12 charities interviewed, **the majority (including small charities) are attempting to work with and involve more academics.** Collaborations between mental health charities and academics are growing.

A few interviewees mentioned that there is a significant opportunity for academics to become more involved and engaged in helping the voluntary sector to improve the evidence base for its work, by co-producing evidence with the sector and disseminating evidence they produce more widely to the voluntary sector. Cross-sectoral collaborations such as that for the Time to Change project evaluation as well as the Peer Support Mentoring project evaluation are illustrating how these collaborations are starting to take place on a larger-scale, improving the evidence base for specific charity sector interventions.

Important knowledge-sharing networks such as the Alliance of Mental Health Research Funders and strategic clinical networks could play a key role in shaping a collaborative agenda around mental health evidence relevant to mental health charities. Strategic clinical networks bring together those who use, provide and commission the service to make improvements in outcomes for complex patient pathways using an integrated, whole system approach. The charity Mental Health Concern mentioned how it is benefiting significantly from its involvement in a strategic clinical network in mental health.

Box 7: The Alliance of Mental Health Research Funders

This is a membership body made up of charities and foundations that support mental health research. It meets regularly to share progress and generate new ideas for improving mental health research in the UK. Members include: BACP; Bipolar UK; Centre for Mental Health; James Wentworth-Stanley Memorial Fund (a charitable foundation); Maudsley Charity; MQ: Transforming Mental Health; The McPin Foundation; The Mental Health Foundation; Mental Health Research UK; and the Waterloo Foundation.

Mental health research charities, such as MQ: Transforming Mental Health and Mental Health Research UK (MHRUK) also have an important role to play in funding and increasing the amount of evidence available for the voluntary sector to draw upon.

Box 8: MQ: Transforming Mental Health

MQ: Transforming Mental Health is a new charity formed to fund much-needed research into mental health. It supports collaborative research across all the biological, psychological and social sciences, from laboratory work, experimental psychology, clinical trials, and prevention studies. MQ's research portfolio is currently focused on three specific themes: 1) Research that will improve the impact of currently available treatments, both psychological and medical; 2) Research that will illuminate the causes of mental illness and lead to better strategies for diagnosis, treatment and prevention; and 3) Support for the best and most innovative researchers who will be the thought leaders of the future.

Section 3: Discussion

3.1. Giving Evidence's work on other sectors

During our interviews, some charities / experts expressed interest in understanding how the mental health charity sector compares to other charity sectors in terms of production, synthesis, dissemination and use of evidence. In summary, many issues that we found in the mental health sector mirror those that we have encountered elsewhere in the voluntary sector. For example:

Production of evidence

- Limited production of evidence on the kinds of interventions which charities run. For example, in criminal justice Giving Evidence analysed a small sample of UK charities and found that 74% publish no research at all about their effectiveness.[xxvi] Sometimes, research on interventions run by charities is produced by outsiders, but even then it is often scarce. E.g., in education in less economically developed countries, taking one type of evidence (RCTs, between 1990 and 2010), there were only 13 RCTs of educational interventions. [xxvii]

- Charity-generated research is often poor quality. This matters because poor quality evidence is likely to be inaccurate and hence misleading. This is discussed further in Appendix 2.

- Evidence produced by charities is not used optimally as a learning tool, but rather is often primarily used with funders. This is backed up by other research done into why charities produce evaluations as discussed in Appendix 4.

- There are no commonly agreed set of outcome measures, even within narrow sector areas, to enable benchmarking across organisations and interventions.

Synthesis of evidence

- In UK criminal justice, the evidence produced by charities is rarely included in systematic reviews, largely because its quality is too low. For example, of the 86 evaluations of arts-based practice with offenders in England and Wales in a sector 'evidence library' in 2013, only four met the quality criteria for inclusion in a 'rapid evidence assessment' commissioned by the National Offender Management Service (NOMS). [xxviii]

- We have relatively rarely heard charities or charitable funders talk about using or commissioning systematic reviews. Some do, e.g., Giving Evidence has recently completed one about UK outdoor learning[xxix] commissioned by a funder active in that area, and is currently doing another[xxx] commissioned by the membership bodies of Sail Training organisations, to inform practitioners' work.

- More common for charities to use and produce are literature reviews, which are less structured (and hence more open to omissions and bias) than systematic reviews.

Dissemination of evidence

- Dissemination channels are weak. Charities mainly disseminate material through websites, and newsletters, and/or through conferences. There is no central repository for charities research or a standard way for charities to 'tag' their research online to make it easier to find.

- There are no standards or templates for research reporting. As a result, interventions and research methods are often inadequately described.

Use of evidence

- Research produced by charities does not seem to be used very much outside the organisation whose work it studies (it is not, for example, included in systematic reviews).

- Few players use third-party evidence when making decisions. Some are unaware of the evidence that exists, since research is normally quite separate from practice. In addition, charities feel that existing research may not be applicable to their intervention if it studied work in a different context. The issue of barriers to generalisability is discussed in Appendix 5.

There are some initiatives in other sectors which are attempting to improve the evidence-base, including:

- 'What Works Centres' launched by the UK government in 2013 to identify good practice in a particular area and improve policy and outcomes there.

- The Justice Data Lab run by the Ministry of Justice (MoJ) which gives organisations working with offenders access to central re-offending data. Organisations submit details of offenders they have worked with to MoJ and statisticians find them in the Police National Computer and report back the aggregate re-offending rate and frequency of re-offending. MoJ also provides a re-offending rate for a statistically-matched control group. This helps organisations to assess the impact of their work on reducing re-offending and also helps develop an understanding of effective rehabilitation.

More detail from Giving Evidence's work in criminal justice and education in less economically developed countries is in Appendix 2.

3.2. Recommendations for the mental health sector

Initiatives to promote use of evidence in the mental health sector need to be supported by the sector and to respond to its specific needs. The ideas below come both from Giving Evidence's work in various sectors, and from suggestions from our interviewees. They are intended to prompt discussion, and to begin and shape a dialogue with the mental health sector around the issue of evidence.

By itself, the sector cannot solve all of the issues that have emerged in this report in relation to the evidence system and it needs to co-opt and collaborate with other sectors.

Giving Evidence appreciates that most of the recommendations outlined below take time, skills and

money, and **hence that funders need to be involved and supportive and the academic sector needs to engage further with the voluntary sector.**

3.2.1. Producing evidence

Recommendation 1: Work together with other bodies and academics to prioritise unanswered questions relating to the mental health charity sector evidence base. This can ensure that research resources are directed to where they are most needed, e.g., to improving the evidence for key interventions

Recommendation 2: Co-produce research with the academic sector on those priority questions

A central tenet of clinical research is to '***ask an important question and answer it reliably***'[xxxi]. In common with other charitable sectors which Giving Evidence has analysed, the mental health sector might benefit from using this: that is, working together to identify and agree which questions are important, and then ensuring that they are answered reliably. Often, without that, research addresses many questions, some of which are not really important, and the research resources are spread too thin for the research to answer them reliably.

Ask an important question:
- Charities could work together – with people affected by mental health problems, policy-makers, and specialist research producers such as academics – to prioritise unanswered questions. A helpful model could be the James Lind Alliance, which has worked with some parts of the mental health sector to prioritise research topics (e.g., depression). Its work is outlined below in Box 9.
- Charities would value better visibility about upcoming academic research in which they might participate, in order to ensure its relevance to their work.

Answer it reliably:
- Rigorous, high-quality evaluation research needs to be produced to address the priority questions.
- Research should be produced by organisations able to answer the questions well.
  This may not be operational, service-delivery charities, who are not specialised in research – and nor do they have incentives to do reliable research, since it may be less flattering than poor quality research (see Appendix 3). Rather it may be research specialists. Clearly there needs to be collaboration between them in order to ensure that the practitioners understand and can absorb the research implications. We heard from both academics and charity interviewees that they are keen to continue and to expand their collaborations in order to create high quality evidence.

Gaps in the current research
Several interviewees talked about how they need more evidence about:
- Psychosocial / community-based interventions. They feel that most research currently available concerns medical interventions.
- 'Sub-clinical services' i.e., services outside the health system which aim to prevent people from reaching the threshold for statutory services.
- Well-being, public mental health and resilience.

Box 9: Prioritising research topics – The James Lind Alliance

In medical research, there is a terrible mismatch between the topics which get researched and the topics which concern patients. To address this, The James Lind Alliance (JLA), a UK not-for-profit organisation, seeks to influence research priorities, to ensure that research addresses issues which concern patients, rather than those which concern academics or journals or nobody. Acne is an example which had been largely overlooked by researchers. In its work on asthma, the JLA found that patients were keen to know if there is value in the breathing exercises they're asked to do, which researchers had overlooked.[xxxii]

The JLA convenes patients affected by a particular condition (say, asthma or Parkinson's) together with their carers and clinicians, and runs a structured consultation exercise to identify 'unanswered questions' about the effects of treatments, and to collectively prioritise the top 10 questions[xxxiii]. These Priority Setting Partnerships (PSPs) are often initiated by patient groups,[xxxiv] or by doctors or hospitals interested in an area underrepresented in health research.

The James Lind Alliance has run PSPs in bipolar, depression, eating disorders and schizophrenia.

Recommendation 3: Explore ways for the academic, statutory sector and voluntary sector to engage more around production and using evidence

For example, it may be useful to share (anonymised) data with statutory bodies, since they uniquely hold some of the useful outcome data. More charities could also make use of existing initiatives such as strategic clinical networks which provide a forum for mental health knowledge-sharing.

Recommendation 4: Investigate how funders can support initiatives to reliably answer the important priority questions

Answering the priority questions identified will require funding. However, it may not (always) require more funding than is currently in the system, given that we heard charities talk about being 'forced' by funders to do many pieces of research each on budgets too small to be reliable, whereas the collective budget would have enabled a smaller number of good pieces of research.

In this new model, some programmes will not be evaluated at all, in the interests of investigating a few questions reliably. That is sensible from a research perspective but not evaluating every programme or service is likely to be a shift for funders who may be used to seeing evaluation (however unreliable) for every programme.

Initiatives to help funders understand their role in the current evidence system and potentially change their behaviours (for example by providing larger budgets for a smaller number of evaluation projects and accepting third-party evidence) could be fruitful. Some such initiatives at the institutional funding level are already underway.

Recommendation 5: Improve common measurement of the impact of mental health charity interventions

The objective of evaluation research is to enable good decisions (though this purpose often seems to get lost), and that requires research which compares interventions. Hence the mental health sector may want to look to create and promote:

- Better measurement tools and methods for mental health conditions, particularly related to wellbeing.
- A common set of outcome measures for the mental health charity sector (Box 10 below discusses common outcome measures used in health).

Box 10: Common outcome measures

Many clinical trials define their own outcome measures. This confounds comparison and excludes them from syntheses. For example, a study of 196 RCTs of nonsteroidal anti-inflammatory drugs for rheumatoid arthritis found 70 outcomes were used, and in 2000 trials in schizophrenia, 640 different instruments were, 369 of them only once[xxxv].

A response is the COMET (Core Outcome Measures in Effectiveness Trials) Initiative. COMET seeks to develop 'Core Outcome Sets' for all trials in a specific area of health research, which are agreed minimum sets of outcomes or outcome measures for various areas of study.[xxxvi] Researchers can have whatever outcomes they like, but should use all the outcomes in the COMET set.

There are agreed core outcome sets for rheumatoid arthritis, osteoarthritis, osteoporosis, and psoriasis/psoriatic arthritis.[xxxvii] Steps have also been taken to find core outcome measures for studies into the treatment of asthma.[xxxviii]

We understand that there are several initiatives underway to improve measurement within the mental health voluntary sector such as COMET for bipolar and schizophrenia.

3.2.2. Synthesising evidence

Recommendation 6: Increase the synthesis of evidence relating to mental health charity sector interventions

A good synthesis is much cheaper, and more reliable, than a single piece of primary research.

Good research synthesis only includes high quality evidence (that is, good research designs which are well-executed), and normally only causal investigations. Hence we suspect that research produced by charities is little used in synthesis (and indeed found that to be the case in UK criminal justice: see Appendix 2.)

Mental health charities could move more towards producing / commissioning syntheses of evidence relating to their priority questions. As with primary research, producing good syntheses is a specialism and charities should only do it if they have the skills; otherwise it should be outsourced to relevant experts.

They may also want to use existing syntheses, such as Cochrane Collaboration reviews, Campbell Collaboration reviews, and others.

3.2.3. Disseminating evidence

Recommendation 7: Improve the clarity of research reporting by the mental health charity sector

It might be more helpful if the details of research – whether produced by charities or others – were more clearly reported e.g., if research reports explained the research question, methods, how the method was used (e.g., how the sample was chosen, sample size, survey scripts), and results. This would help people reading / using / synthesising the research to see its quality, and also help practitioners to see whether it relates to their context. The mental health sector could experiment with a 'checklist' of items to include in reports of research that it produces (medicine has several for the various types of research, and Giving Evidence worked with the criminal justice sector to produce one[xxix]).

Recommendation 8: Strengthen the infrastructure around the storing of relevant charity sector evidence

The mental health sector could strengthen the infrastructure around research that it produces to make it easier to locate. This could be creating a repository, or meta-data tagging and a website with a 'crawler bot' (again, Giving Evidence explored creating one for the criminal justice sector[xl]).

3.2.4. Using evidence

Recommendation 9: Identify what is needed for mental health charities to make greater use of the existing research

Perhaps service-delivery mental health charities could better use evidence which already exists rather than *producing* their own. Research could more usefully be seen as an input into learning and development, rather than as a 'product'.

Some of them may need new skills to understand, interpret and apply research. A few smaller charities feel that they could benefit from (pro-bono) help to audit and suggest improvements about their production and use of evidence. Well-written lay-person versions of research could improve uptake by people who are less research literate.

Appendix 1:
Project method detail

Inclusion / exclusion criteria for mental health charities participating in study

In order to understand the evidence system, Giving Evidence conducted qualitative interviews with mental health charities that met the following criteria:

- Provide services to adults suffering from mental health problems. Mental health problems included / excluded as per the National Statistics 2000 study on Psychiatric Morbidity of Adults Living in Private Households.[11] Mental health need not be the charity's main or sole focus but it is key that they provide some mental health services;
- Any size, geography, age, type of service.

Charity recruitment

Giving Evidence developed a target charity contact list through word-of-mouth recommendations or referrals, a review of literature relating to mental health charities as well as an analysis of members of one mental health network – the Mental Health Alliance. It did not attempt to establish a strictly representative group of charities but hoped to include a mix of small, medium and large mental health service delivery charities operating across the UK so as to determine how far the issues relating to the evidence system were dependent on the size and resources of the charity.

Giving Evidence recruited charities to interview through diverse channels: an e-mail about the study was sent to Mental Health Alliance members and Giving Evidence followed up with members that met the inclusion criteria; some charities were referred by contacts; and some charities were contacted directly without a referral.

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11 Includes the following ICD-10 categories of mental or behavioural disorder: schizophrenia, schizotypal and delusional disorder; mood (affective) disorders; neurotic, stress-related and somatoform disorders; behavioural syndromes associated with physiological factors; disorders of adult personality and behaviour. It excludes the following ICD-10 categories of mental or behavioural disorder: organic mental disorders; disorders of psychological development; behavioural and emotional disorders with onset in childhood; mental retardation.

Charities interviewed

Giving Evidence interviewed 14 service delivery charities of which 12 were happy for the content of the interviews to be included in the study. In the table below, small refers to charities with less than £1m of mental health service delivery spend; medium refers to charities with between £1m and £5m of mental health service delivery spend and large refers to charities with over £5m of mental health service delivery spend.

Charity	Description	Mental health Service Delivery Size	Geography they serve
Dundee Association for Mental Health	Provides facilities within the community for people suffering from or recovering from the effects of mental ill health and their friends and relatives.	Small	Dundee, Scotland
Family Action	Supports over 45,000 families and children each year via 130 community-based services across the UK.	Large	UK
Fircroft Trust	Includes resource centre with residential facilities.	Small	Kingston, London
Hafal	Works with people recovering from serious mental illness, their families and carers. Has 191 staff and 150 volunteers helping over 1,000 people affected.	Large	Wales
Jami	Treats, cares, supports, educates, trains and rehabilitates Jewish people suffering from various forms of mental health problems. Treats approximately 840 individuals.	Medium	Barnet, London
Mental Health Concern	Provides wide range of services for over 10,000 people a year.	Large	North-East of England
Mind	Provides information/support, campaigns and runs a network of over 140 local Minds.	Large	UK
Mind Stockton and Middlesbrough	Provides services for approximately 3,000 people a year who have experienced emotional or mental health problems and their families.	Medium	Middlesbrough/ Stockton
Richmond Fellowship	One of the biggest voluntary sector providers of mental health support offering a wide range of housing, care, employment and community support across more than 120 services.	Large	England
Samaritans	Suicide reduction charity supporting people at risk of suicide and who are in emotional distress.	Large	UK & ROI
Sane	Emotional support and information for people affected by mental health problems.	Small	UK
Thrive	Delivers programmes at 4 centres, provides an information service, training and consultancy.	Medium	UK

The number of charities interviewed is small, which means that findings must be approached with some caution. An initial understanding of the key issues relating to the production, synthesis, dissemination and use of evidence was developed through the interviews, but inclusion of a larger amount of charities would increase confidence in the conclusions.

There is likely to be bias within the group of charities interviewed as charities that produce and use evidence are more likely to be: a) interested in this project; and b) want to participate.

Giving Evidence also met sector experts including the Centre for Mental Health, Transforming MQ and the McPin Foundation to gain context about mental health research as it relates to the charity sector.

Method

Interviews were 60-90 minutes with the key person(s) responsible in the charity for research, monitoring and evaluation and followed up by e-mail on any outstanding questions. Interviews were a mix of face-to-face and via telephone. For the majority of interviews, two interviewers from Giving Evidence were present. Giving Evidence performed semi-structured interviews using the interview guide below.

The interviews were not recorded or transcribed due to budgeting reasons. Written notes were taken during the interview and the interview was written up afterwards and provided to the interviewee, if requested.

In preparation for each interview, Giving Evidence reviewed the charity's website and key published information including annual reports. An analyst coded the qualitative interviews according to key themes pertaining to the evidence system for inclusion in the report.

Interview questionnaire

1. Warm-up/Overview Section

   a) Describe the project and ask if there are any questions about it.

   b) How long have you been in the organisation and what is your role?
      Note: probe how role is connected to monitoring / evaluation / research.

   c) What is your organisation's general approach to research, monitoring and evaluation? How has this evolved over time? What do you find the greatest challenges in this area?
      Note: make sure to note how interviewee describes and what he/she thinks of the terms research, monitoring, evaluation.

   d) How would you describe the current state of evaluation and research in the mental health charity sector?

2. Detail on Organisation's Own Research, Monitoring and Evaluation

   a) Who is responsible in the organisation for monitoring / evaluation / research?
      Note: probe to understand where monitoring / evaluation / research fits in the organisational structure.

   b) How much do you spend annually on monitoring and evaluation? (ensure to understand how they break this down).

c) Can you describe in detail the monitoring and/or evaluation of your services that your organisation has done over the last 5 years:
Note: probe to understand:

- the different types of monitoring / evaluation (impact evaluations, process evaluations, formative evaluations, beneficiary consultation, monitoring of inputs / activities, monitoring of outputs, monitoring of outcomes)
- the different methods used for monitoring / evaluation as well as sample sizes / design details
- for each evaluation, who funded it and how much did it cost
- for each evaluation, who conducted the work (staff, academics, contractors).

d) Why have you done these?
Note: probe on how much has been internally driven or funder driven.

e) What have you used them for?
Note: probe to understand specific examples of use.

f) What have you learnt from them? How have they / do they contribute to the organisation's development?
Note: specific examples of how evaluations have affected internal decisions

- Contributing to strategy
- Contributing to programme development (e.g., contributing to decision to stop / adjust / change programme or to the design of new programme) .

g) With whom have you shared the monitoring / evaluation / research? If so, why? If not, why not?
Note: probe to get specific examples of how the information has been shared and used by other players.

h) Have you published any of your monitoring / evaluation / research?
Note: probe to understand:

- Where they are published:
    - own website
    - annual report
    - journal
    - conference
- Why they are published:
    - funder-led
    - internally-driven
- If they weren't published, why not?
    - Lack of confidence about basic data
    - Lack of confidence about analysis
    - Concern about giving away too much information to the competition
    - Don't know where to
    - Lack of internal skills
    - Lack of internal resources

- Don't think it is useful to others
- No reason to
- Other.

i) If you have shared and/or published monitoring / evaluation / research, how many people do you think have read it or have been influenced by it?
Note: concrete examples.

3.   Detail on Research Uptake

a) Do you use other organisation's research / evaluations? Whose? What?
Note: get specific examples. Try to understand what information is digested on a regular basis e.g., newsletters, journals.

b) What do you use them for?
- New programme design / development
- Existing programme design / development
- Competitor benchmarking
- Strategic development
- Advocacy
- Other.

c) How did you find it?

d) How useful and clear was it?

4. Conclusion / Changing the Status Quo

a) Do you think that there is good evidence from yourself or others about the impact of the services you offer?

b) In general, do you think that there is a good evidence base in the mental health sector for the different types of services that mental health charities offer?

c) Do you think that there needs to be more evidence created by/for and used by mental health charities? What does the mental health charity sector and external parties (e.g., academics) need to do differently?

d) If you had a big pot of money to improve the evidence base for mental health charities, what would you use it to do?

e) What do you think needs to change for this to happen? What are the key barriers to change

Appendix 2: Conclusions from Giving Evidence research into the evidence systems in criminal justice in the UK and education in less economically developed countries

1. Evidence System for Criminal Justice Charities in the UK

In 2014, Giving Evidence looked at the current evidence system for criminal justice charities in the UK, as part of a consultation about improving it. Below are some key findings – greater detail can be found in the project report[xli].

Production of evidence

- **Little evidence** is published by criminal justice charities. Giving Evidence analysed a small sample of UK charities working in criminal justice, and found that 74% publish no research at all about their effectiveness.

- **There may be quality issues in the research that is produced by criminal justice charities.** For example, the Arts Alliance is a coalition of arts organisations working in the UK criminal justice system, managed by Clinks, the umbrella body of the voluntary sector working with offenders in England and Wales. Its 'evidence library' contains evaluations of arts-based practice. In 2013, it had 86 evaluations, only four of which met the quality criteria for inclusion in a 'rapid evidence assessment' commissioned by the National Offender Management Service (NOMS) [xlii] The UK's new What Works Centre on Crime Reduction has identified 337 systematic reviews in crime reduction. Though the Centre hasn't rigorously coded those systematic reviews for the source of the studies included, it said that the amount of charity-generated research included in them was 'very little'.[xliii]

- **There are some exciting new initiatives to improve the evidence base on crime reduction.**
  - In 2013, the UK government launched several 'What Works Centres', each tasked with identifying good practice in a particular area and improving policy and outcomes there. The What Works Centre on Crime Reduction is led by the College of Policing, supported for three years by a consortium of universities. Its initial tasks include listing all systematic reviews relevant to crime reduction, rating and ranking them so as to identify effective interventions, producing guidance for practitioners (the police and others), and training practitioners. Whereas systematic reviews often largely look at *whether* something works, the What Works Centre on Crime Reduction is also focused on understanding *why* it worked (or didn't), what enables and hinders it, the contexts in which it might succeed, and what implementers need to know in order to implement it.

- **The Justice Data Lab,** currently being piloted by the Ministry of Justice, aims to solve the problem of charities working with offenders struggling to gather data from which to assess whether and which parts of their services are working because they cannot track their beneficiaries over time (sometimes for legal reasons) and/or they cannot see data on whether and how their beneficiaries re-offend. The state alone has those data. With the Justice Data Lab, charities submit data about offenders with whom they have worked and the services they have provided, and the lab returns to them the one-year re-offending rate for that group and that of a matched control group of similar offenders. The method is published by the Ministry of Justice, though clearly sample sizes vary and hence the statistical significance of results varies.

Dissemination of evidence

- **For research published by criminal justice charities, there are (as far as Giving Evidence could find) no standards or templates for what is reported**. Charities appear to publish as much or as little information as they see fit, in whatever sequence they want, and publish it wherever they want or can.
- **Giving Evidence heard complaints that charities often inadequately describe their interventions and their research methods**. This prevents their research from being included in systematic reviews, and prevents the interventions being replicated. This latter may be in part intentional – or, at best, a response to a badly-designed incentive: when charities compete for contracts from commissioners, their interventions are their products, their IP. This provides a strong financial incentive to protect their 'secret sauce'. This is a problem on two counts. First, many successful programmes serve a need larger than their inventor-organisations can serve and hence replication by other organisations is necessary for reducing crime and creating justice as fast as possible. And second, replication is essential for testing whether the research results were accurate.
- Charities said that they mainly disseminate material through websites, and newsletters, and/or through conferences and umbrella organisations.
- **There is no standard place for criminal justice charities to publish their material** – unlike, say, medicine or academia which uses journals and databases of journal abstracts. **Neither are there standard ways for charities to 'tag' their research online** (i.e., metadata) to ensure that it is findable through search. That is, the information infrastructure (also called information architecture) is weak: good information architecture allows the user to find all and only what they want relatively swiftly.

Use of evidence

- **Research produced by criminal justice charities did not seem to be used very much**. We gathered that, for most actors in the sector, when they want reliable answers, they turn to the academic literature.

2. Evidence System for Education in Less Economically Developed Countries (LEDCs)

Giving Evidence analysed the evidence in education in LEDCs aiming to identify institutions, skills, resources, relationships, culture and funding systems which would bolster the use of evidence in education in LEDCs. Below are some key findings – greater detail is in the project report.[xliv]

Production of evidence

- **Very little evidence is produced, both on learning levels and on effectiveness**. For example, only three high-quality studies have ever examined the effects of blackboards on test scores, and no studies looked at the effect of teacher absenteeism or school meals on students' time in school, despite these being very popular interventions. The effect of building new schools – much beloved of donors – has only been studied three times.[xlv] Taking one type of evidence, RCTs, the 20 years between 1990 and 2010 saw only 13 RCTs on interventions in LEDCs.[xlvi]
- **Funding for research about education is limited**. In the UK, for example, government spending on health research (domestically) was nearly 60 times greater than that on education research in 2010-2011. [xlvii] In 2014, DFID spent £75 million on research into LEDCs, but less than £0.5 million on education research.[xlviii]
- **There are two 'tribes' of researchers (mainly academics)** researching causal and non-causal parts of education (economists and educationalists, respectively). There is little mutual respect, little contact or reading of each other's materials and neither tribe is particularly close to practitioners or policy-makers.
- **There is limited demand for evidence from teachers, policy-makers and practitioners.**
- **Research in education is normally quite separate from practice.**

Synthesis

- **There are few (if any) guidelines or translation of evidence in the field of educational research**, so research is hard to interpret or use for practitioners. The curriculum is the nearest to a 'guideline' but it is quite different (normally offering no advice on 'how' to teach) and changing it often requires legislative or other bureaucratic change: hence it is unresponsive to new findings.

Dissemination

- **Few (if any) dissemination channels reach practitioners or policy-makers**. Journals are not aimed at practitioners, but at other researchers. Academics present research at conferences organised by the World Bank or national-level policy-makers, but little reaches schools and teachers.

Use

- **Few potential users of evidence in education (teachers, schools, policy-makers, programme managers etc.) use evidence effectively**. For example, some of the largest funders of education programmes in LEDCs indicated to Giving Evidence that they did not review evidence before making their decisions. Similarly programme managers of some large programme said that they use their own findings on the effectiveness of certain interventions, but did not seek evidence from elsewhere.
- **Users of evidence** cannot integrate research into their practice because they do not know that the evidence exists. This ignorance arises partly from the lack of 'push' dissemination mechanisms.

Appendix 3: Reflections about why the quality of research methods matters

i) Because different research methods give different answers

"Two men say they're Jesus: One of them must be wrong" (Dire Straits lyric!)

The table below shows the effect of a reading programme in India measured using several research methods[xlix]. These methods all used the same outcome measure (change in reading test score, out of 100), but the research designs were different.

The answers vary widely: some suggest that it works well, others show it to be detrimental. Clearly there can only be one correct answer! All the other answers are incorrect: and could mislead donors or practitioners to implement this programme at the expense of another which might be better.

Method	Impact Estimate
(1) Pre-post	26.42*
(2) Simple Difference	-5.05*
(3) Difference-in-Difference	6.82*
(4) Regression	1.92
(5) Randomized Experiment	5.87*

* Statistically significant at the 5% level

The answers vary because research methods vary in how open they are to biases (i.e., systematic errors). For instance, if a study only looks at the outcome (here: reading level) before the programme and then afterwards (i.e., is a pre-post study), we don't know whether any improvement in reading levels was due to the programme or just to the fact that children learn over time anyway.
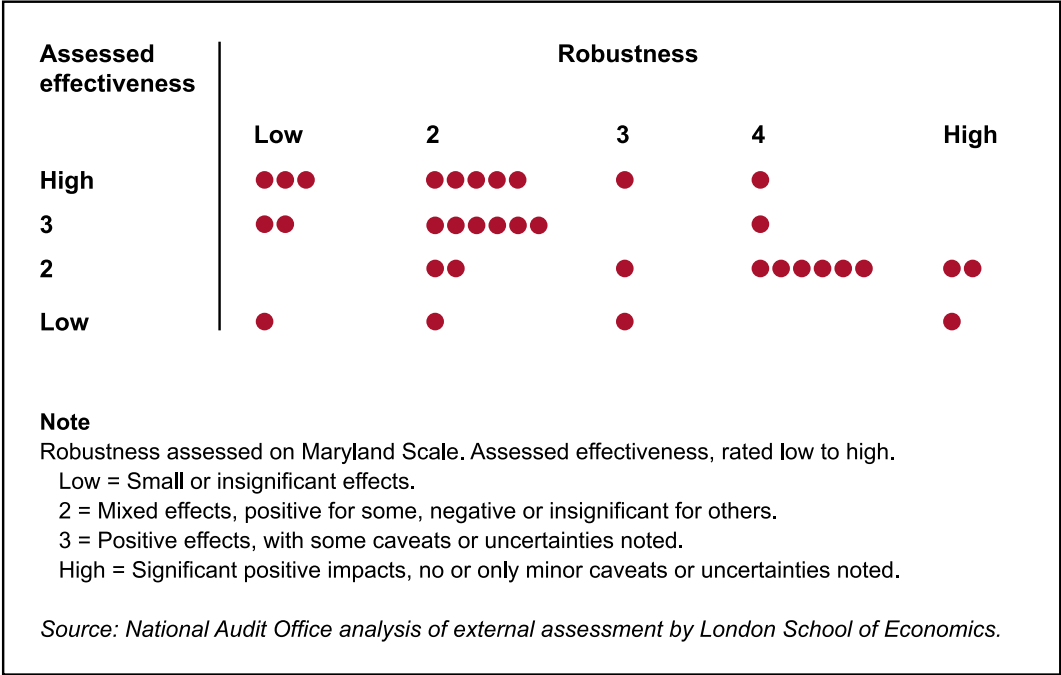
{As an aside, contrary to popular myth, it is not invariably the case that robust research is more expensive than unreliable research, nor that randomised controlled trials (the most reliable design for a single primary study) are invariably terribly expensive: many are cheap or free.}

ii) Because weaker research methods allow for more positive findings

The UK National Audit Office searched for literally every published evaluation of a UK government programme[l]. Of those, it chose a sample, and ranked on one hand, the quality of the research method ('robustness' on the x axis, i.e., how insulated the study is from bias), and on the other, the positive-ness of the programme ('claimed impact').

The trend line on the resulting graph below would slope diagonally downwards. It shows that more robust research only allows for modest impact claims whereas weak research allows much stronger claims.

Figure 8: Relationship between robustness and claimed impacts in evaluations

Assessed effectiveness	Robustness				
	Low	2	3	4	High
High	●●●	●●●●●	●	●	
3	●●	●●●●●●		●	
2		●●	●	●●●●●●	●●
Low	●	●	●		●

Note
Robustness assessed on Maryland Scale. Assessed effectiveness, rated low to high.
　Low = Small or insignificant effects.
　2 = Mixed effects, positive for some, negative or insignificant for others.
　3 = Positive effects, with some caveats or uncertainties noted.
　High = Significant positive impacts, no or only minor caveats or uncertainties noted.

Source: National Audit Office analysis of external assessment by London School of Economics.

Bad research can be persuaded to say almost anything, and won't allow researchers to distinguish the effects of a programme from other factors (e.g., the passage of time, the mindset of participants, other programmes) nor from chance.

Most social interventions have a small effect and a reliable research method will show what that is: bad research is likely to overstate it. The highest estimate for the reading programme above is from the pre-post study which is a weak study design.

This relationship between weak research methods and positive findings has been shown in many social interventions and also in medical research.

Appendix 4: Reflections about why charities produce evaluations

When asked why they measure the impact of their work, seven times as many UK charities cited funders' requirements as cited, 'wanting to improve our services' (52% against 7%).[li] This suggests that charities' evaluations and impact research are often largely motivated by the need to raise funds.

Figure 9: Drivers for increasing impact measurement efforts
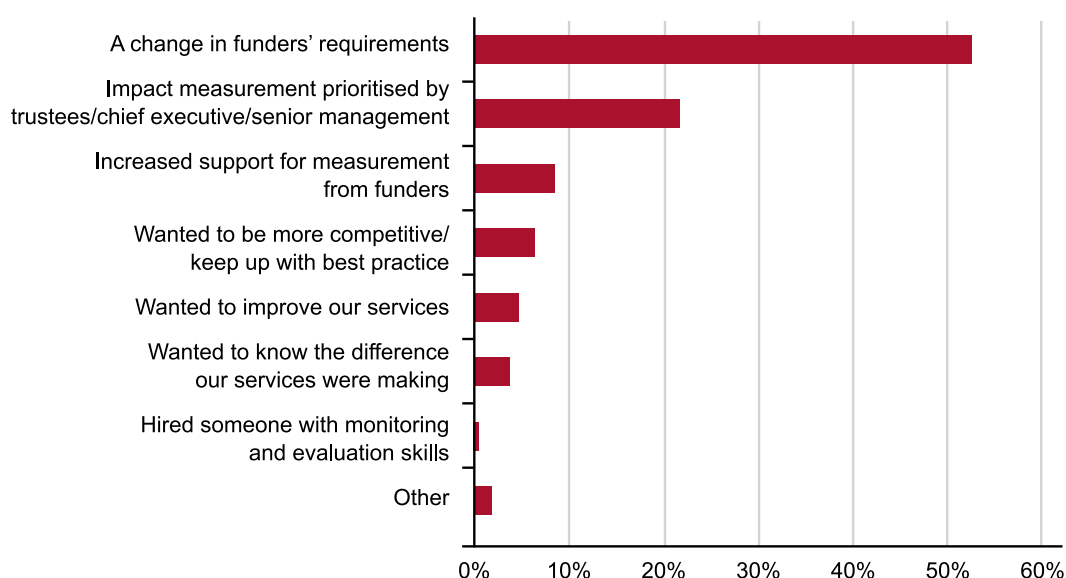
Question: What were the main reasons for this increase [in impact measurement efforts?] N=550

Other evidence suggests that charities may only undertake impact research which is likely to flatter them. A clever rigorous study by two American universities investigated this. In a randomised controlled trial, 1,419 micro-finance institutions (MFIs) were invited to join a study of the effectiveness of micro-finance. Some of the invitation letters included references to (real) research suggesting that micro-finance has a positive effect; other letters included references to (also real) research of similar designs and by the same researchers suggesting that micro-finance has zero or negative effect. MFIs receiving the former letter – i.e., whose expectations were set that the research might flatter their work - were 'significantly' more likely to want to get involved.

Funders and commissioners (arguably) amplify this incentive by requiring charities to include assessments of their effectiveness in applications and tenders for commissioned services.

Appendix 5: Reflections about barriers to generalisability

Two issues are often cited as reasons why research cannot be used beyond its original context – or should only be used elsewhere with caution. They are quite different.

Barrier	Description
Fidelity	This concerns the question: Did all the beneficiaries receive the same intervention? That is, is what was delivered true to what was supposed to be delivered? Fidelity is high if 20 patients are given the same pill in the same dosage and in the same way. It is lower if they all have breast cancer removed, because (a) the surgery may be performed differently by different surgeons, and (b) the patients may have different conditions. Fidelity is lower still for patients receiving a 'talking therapy', since clearly the therapist responds to what the patient says, which will be different in each case. Fidelity is low whenever there is scope for people to change what is done. Fidelity is generally low in educational settings, for example, because teachers differ in their styles, respond to their students, so effectively students get a range of interventions, and resources vary between schools, e.g., some have no roof.
External validity	This concerns the question: if an intervention works in one context, will it work elsewhere? External validity considers whether the results of research (including experiments) will be true in a different context. External validity is high in physics – the speed of light is the same in Japan as in Jamaica (although external validity is not always high even in physics: gravity's strength varies between Sweden and Singapore). People often say that external validity is high in medicine ('everybody reacts the same way to a pill') though this isn't always true – for example, people of different races, sizes and genders metabolise drugs differently. External validity is low whenever context is important, as it is for most 'social' interventions, for example some in mental health. For instance, the Nurse-Family Partnerships which support poor pregnant women in the US achieve a great deal, but they achieve much less in the UK. In the US, the counterfactual (what those women would receive without that intervention) is very little, whereas in the UK they would get NHS support which is pretty good.

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