Informing Mindfulness: investigating how national information can support the implementation and further research and development of mindfulness-based approaches to improve the health and wellbeing of citizens.

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A research proposal for an MA thesis in mindfulness-based approaches.

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Introduction

As the mindfulness community develops, the move from a scientifically-proven set of mindfulness-based interventions (MBIs) to a comprehensive range of services delivered by professionals will require substantial information to justify, cost, plan, implement and monitor those services. Also, to further develop MBIs, clinical trial data would be usefully supplemented by good quality population-based data; contrast the study by Kuyken et al (2014) that used data specifically collected from 424 individuals to assess a hypothesis on MBCT with Hwang et al (2014) that used 42,082 data points from routinely collected data to assess a hypothesis on bowel cancer screening and it is easy to see the potential value of national data to accelerate and enhance the quality of scientific investigations.

The mindfulness community is in an early phase of development. A thorough understanding of current national data and how to influence the national agendas to obtain more relevant data will accelerate the uptake of MBIs and the more general pervasiveness of mindfulness-based approaches as a contributor to wellbeing. The community is currently moving from a scientific evidence base (Kuyken et al, 2008) and clinical acceptance (NICE, 2009) through political aspiration (Mindfulness Initiative, 2015), towards policy development. This will require ever richer information (Rycroft-Malone, J. et al, 2014).

The feasibility of achieving value from national data is high. Established clinical specialties, such as cardiac, renal and cancer, already have substantial data used to support research and development as well as commissioning of services and quality assurance. Building on the experiences and success of those domains, the mindfulness community should be able to move quickly to support its goals with high quality, comprehensive data.

2.1 Research question

The research question to be addressed is: how can nationally collected data and information support the mindfulness community in the implementation, development and research of mindfulness-based interventions, and more generally provide insight into the effects of mindfulness on the health and wellbeing of individuals? More specifically that will involve understanding the aspirations of the mindfulness community and how they can be supported by national data, understanding relevant aspects of the national informatics agenda, informing the mindfulness community of what is possible, determining short term actions to benefit from existing data, and providing an implementable long-term plan to develop a national approach to data to support mindfulness.

2.2 Background

Data is a critical resource in delivering effective care, is recognised nationally at the most senior levels (Sood, Maruthappu & Keogh, 2014), and there is a national information strategy for care (Department of Health, 2012). Substantial data is collected nationally to support health and social care in the UK. For example, the Health and Social Care Information Centre (HSCIC) collect data about each and every hospital stay in England (HSCIC, 2015), summarising diseases and interventions that can be linked to other data, e.g. Symmonds et al (2014). Many specialties have datasets with much richer information. In addition agencies such as the Office of National Statistics , Public Health England (PHE) and the Health and Safety Executive (HSE) collect data on various aspects of health, behaviour and wellbeing.

Mindfulness does not appear in this data, with the exception of the Improving Access to Psychological Therapies (IAPT) dataset (Clark, 2012) (IAPT, 2011). Unfortunately, mindfulness is not properly represented in that dataset even though MBCT is a NICE recommended IAPT therapy (NICE, 2009). Enquiries with the HSCIC (appendix A) demonstrate that current data collected on mindfulness in IAPT is negligible. In part that represents low adoption of MBCT, but considering the national standards that support the IAPT dataset (Appendix A), they are ambiguous, incomplete and potentially misleading, so the data for mindfulness cannot be relied upon and will not be usable without some change to the national standards.

The Aspire project (Rycroft-Malone et al 2014) is a qualitative investigation into the implementation of MBCT. Its aim is to understand the broad issues affecting take-up. It is still underway, and there are, as yet, no publishable conclusions. The data gathered by Aspire should inform this investigation, and the two projects should be complementary. The primary difference will be on focus, with Aspire taking a broader qualitative perspective on the whole area of MBCT implementation and this project focussing more deeply on how quantitative data can support implementation and future research and development of MBIs in general.

The Mindfulness Initiative is presently trying to scope the demand for MBIs and assess the supply side requirements in terms of qualified mindfulness instructors. To support Mindful Nation UK proposals (Mindfulness Initiative, 2015), there will be a need for quantitative data to develop policy and justify investment. That will require data on who might benefit from MBIs and what the economic benefit of that might be: for example, HSE (2014) report 11.3 million annual lost time days for stress, anxiety and depression suggesting an economic cost of £3.5 billion, which raises the question about the potential impact of MBIs in the workplace and how national investment in this could provide economic benefit.

There is no national register of mindfulness instructors, unlike most established professional disciplines. Nor is there a register or of people who have undertaken MBIs. This is a large gap in knowledge, which will make commissioning and planning of services difficult on a national scale.

Current scientific evidence is based on controlled trials, and to undertake longitudinal studies broader data collected over longer periods and linked is

important (Goldring, 2010). Examples like the Human Fertilisation and Embryology Authority's data for quality initiative (HFEA, 2015) will be informative on how to approach this.

Linking of data from multiple sources can be useful for a variety of purposes. The NHS have a unique patient identifier, the NHS number (HSCIC, 2015a), which is also used widely in social care, and there is a national strategy to require universal use of this (Department of Health, 2012). Under controlled procedures (HSCIC, 2014) it is possible to link multiple health and social care records, and provide the ability to ask questions such as "*is there any indication that MBIs have any effect on maternity outcomes, such as incidence of postnatal depression?*" without the need to set up controlled trials.

Overall, there are wide-scale examples of good information supporting health and social care domains. There are opportunities to achieve better information for the mindfulness comment in the short term using established collections, and the potential for much richer information in the medium to long term.

3. Methods
3.1 Sources of information
The understanding of information needs will involve discussion with mindfulness leaders, practitioners and organisations to provide a broad spectrum of needs. The primary source will be the main academic centres, supplemented by information from organisations delivering MBIs. As the understanding develops, a wider survey of the broad community will be obtained through an online questionnaire.

Understanding of current national data will be drawn from public reports by national organisations such as the HSCIC and PHE, supplemented by enquiries through their established channels. Understanding of plans for national data will be drawn from public documents and interviews with staff within those bodies that collect and use national data.

3.2 Procedures to be employed
Though the project is about quantitative data, it is essentially a review. An appropriate established methodology is Checkland's soft systems methodology (Checkland & Poulter, 2006) (Checkland, 2000). This involves collating multiple views, synthesising them and presenting them back in a comprehensive way. It has been applied in health and care settings, for example by Gillies & Galloway (2008). The approach works through examining the problem, expressing it fully, defining relevant technical and social systems, building a conceptual model of human activity systems, comparing models with the real world, defining desirable and feasible changes, and taking action; this project can only propose an action plan, and not act on it. The methodology contains ways of viewing systems at a number of levels of abstraction.

A substantial amount of information can be gleaned from publicly available documents, describing current national data and national strategies and plans for

information. A useful outcome from the project will be a bibliography of such documents.

To understand the broad needs of the mindfulness community, a seminar on national data will be prepared and offered to key centres, and feedback elicited from participants. This will be supplemented by interviews with key individuals. A draft set of needs will be produced and shared widely for review.

To understand the national agenda for data, engagement with national organisations that collect data will be necessary. That can in part be done through their help desk facilities, but for more strategic insight and understanding of national plans there will need to be interviews with staff in those organisations. A draft letter to those organisations is in Appendix B.

The synthesis will produce a "rich picture" (Checkland & Poulter, 2006) of the area of mindfulness information needs, national data sources, national plans, and produce a plan for consideration by the mindfulness community.

4. Results

4.1 Theoretical issues

This project will not directly influence the theoretical aspects of mindfulness. It is an enabling project that will support future projects in the development of theory by highlighting sources of data that can be used to develop theory either on their own or by supplementing other data. The thesis plan below illustrates the way the research question will be addressed.

4.1.1 Chapter 1 - The information needs of the mindfulness community.

This chapter will consider the broad needs of the mindfulness community for national information and data in the short and the long term. The scope will range from broad demographic and pathological data that can inform policy and planning, through data that can support commissioning and planning of services, to detailed data that could support scientific investigation. To determine the feasibility of achieving those needs there will be read-across from specialities where similar information and data has been useful.

4.1.2 Chapter 2 - Current and planned national information of relevance.

This chapter will consider what data already exists that may be of use, and any immediate plans to change that. Preliminary investigations show that small changes to the IAPT dataset could have significant value to supporting the implementation of MBCT, and there may be more such opportunities. The scope will cover broad demographic and economic data through to fine grained data such as patient-level data in the NHS.

4.1.3 Chapter 3 - Additional national data needs for the mindfulness community.

This chapter will consider what additional data may be of value. Particular

attention will be placed on detailed data, such as a register of mindfulness trainers, and a register of those who have undertaken an MBI. Where possible, this should consider small additions or changes to existing data flows, but there may be a need for additional data flows.

4.1.4 Chapter 4 - Ethical dimensions of data.

The use of national data is ethically constrained, and controlled by legislation. The Data Protection Act 2003, the Equalities Act 2010 and the Health and Social Care Act 2012 provide protection to citizens regarding access to and use of national data. Various mechanisms exist in government bodies to control access to and use of data. These constraints and mechanisms will be summarised.

4.1.4 Chapter 4 - Recommended changes to national data.

Considering the gaps between the needs of the mindfulness community and currently available national data, this chapter will propose changes to national data. That will include minor changes to existing data flows, such as the IAPT dataset, changes to planned data flows, and new data flows.

4.1.5 Chapter 5 - A draft information plan for mindfulness.

This chapter will propose a set of changes, with a provisional timetable, and advise on means of achieving this. That will include how to engage with the change processes for agencies that already collect data, and how to commission new data collections. It may be necessary for the mindfulness community to take ownership of some of the collections (e.g. teacher register), and there will be proposals on how to achieve that.

4.2 Personal and process issues

There is a small risk that some information will be difficult to obtain. The author has considerable informatics experience in the NHS and DH at a senior level and is able to quickly assimilate and understand the data and organisational aspects. He is delivering training in mindfulness that gives him some insight into the needs of the community. Therefore the risk of not accessing the right information are low. Where it has been impossible to source information, that will be included in the dissertation with the reasons.

The scope of the project is broad. There are varying approaches to the way data is managed in each of the UK countries. The primary focus will be on England, but where possible there will be read across into Scotland, Wales and Northern Ireland.

Care will need to be taken not to present the results in a judgemental way, and for any criticism of existing systems to be presented in a sensitive and constructive way. All interviews with parties will be fed back to them to correct any misrepresentations. The dissertation will not quote individuals without express permission.

It is not anticipated that there will be a need to request sensitive data. Preliminary investigations suggest that the available data is of limited value without some

changes. However, if there is a need for acquiring such data then ethical approval will be necessary.

This review will consider only data that is either in the public domain, or managed and controlled by public bodies, is unlikely to require access to sensitive information, and will not require interviews with individuals concerning their own personal data or personal data of others. Therefore there should be no need for ethical approval for any of the interviews.

5. Discussion and Conclusions

The development of MBIs, enabling them to become widely used, will require much richer information than is currently available. Without strong arguments backed by quantitative data, national investment in MBI's will be limited and consequently their adoption is likely to be piecemeal. Without information on the capacity of the mindfulness community to deliver against a growing demand, planning will be hampered. Without data on delivery of MBIs, a true picture of national adoption cannot be achieved. Without data on individuals who have participated in an MBI, longitudinal studies on the effectiveness of MBIs will be difficult and expensive. Without the ability to link data on MBIs with pathology and other intervention data, trends and correlations in the population as a whole will be impossible.

This project will be a useful step in allowing the mindfulness community to address shortfalls in national information that are an inevitable consequence of being a discipline at the early stages of its development. It is a challenging project in terms of scope and the need to access governmental organisations, but the rewards could be significant.

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Appendix A - National Recording of Mindfulness in the NHS

The majority of clinical findings and interventions in the NHS are coded into some form of electronic record. There are many reasons for this, such as consistency, reporting and ease of automation. For an intervention to be widely adopted and tracked at a national level, a critical success factor is that it can be recorded electronically in a consistent way. The following information was gleaned through a series of queries presented to the Health and Social Care Information Centre helpdesk, which is open to members of the public.

Mindfulness in the IAPT dataset

Mindfulness Based Cognitive Therapy (MBCT) is a NICE recommended intervention that helps prevent relapse of depression in certain populations. It is therefore a therapy under the national Improving Access to Psychological Therapies (IAPT) programme. A national dataset has been established to monitor therapies delivered under IAPT, collected and reported on by the Health and Social Care Information Centre.

An initial enquiry to the HSCIC has determined that mindfulness-based interventions are reported in the IAPT national dataset. However, the number of interventions are low and do not end up being included in the national publications. Mindfulness is coded in the dataset under the "IAPT psychological therapies", which are described in the NHS data dictionary. The term used by the NHS data dictionary, and hence the IAPT dataset is "mindfulness". There appears to be no prescriptive guidance under which interventions are recorded under "mindfulness" and there are a number of other interventions where mindfulness may be part of that intervention, or there is the possibility that some coding of MBCT is done under CBT.

The fact that there is already a mechanism for tracking adoption of MBCT through an established national dataset that captures the order of 1 million interventions for psychological therapies a year is hugely important. Though the recording of MBCT is low, there is a mechanism for tracking the implementation of MBCT through IAPT services. It would appear that with the IAPT dataset it would be possible to trace where services are being delivered. If it is known that a service is being delivered but not reported in the dataset there would be value in investigating why that is so.

More general questions regarding coding of Mindfulness

IAPT services are not necessarily the only way that MBCT and other mindfulness interventions may be delivered. Most interventions involve GPs in some form. This leads to the question of what information about MBCT and other mindfulness-based interventions are recorded by GPs. GP records in the UK are coded using the terminologies Read 2, CTV3 and SNOMED CT, supported by the UK Terminology Centre. An initial enquiry shows that these terminologies have a term for "mindfulness-based therapy" which is general; normally there would be a term for each particular intervention in these terminologies. These are:

UK SNOMED CT: 75516001 | Psychotherapy (regime/therapy)
933221000000107 | Mindfulness-based therapy (regime/therapy)

Read 2: X71bp | Psychotherapy
Xabo6 | Mindfulness-based therapy

CTV3: 8G... | Psychotherapy/sociotherapy
8GP.. | Mindfulness-based therapy

Therefore it is possible to record a mindfulness-based intervention in GP systems, but it is not precise. Interestingly, the data dictionary term is just "Mindfulness", not "Mindfulness-based therapy", so there is an inconsistency between the two coding systems.

Seeking further clarification regarding the use of the OPCS coding scheme, the HSCIC responded with:

"*We can confirm that there are no specific national standards relating to the coding of Mindfulness Based Cognitive Therapy (MBCT).*

There is therefore nothing precluding the use of any of the following codes to classify MBCT:

X66.1 Cognitive behavioural therapy by unidisciplinary team
X66.2 Cognitive behavioural therapy by multidisciplinary team
X66.8 Other specified cognitive behavioural therapy
X66.9 Unspecified cognitive behavioural therapy

Please note that code assignment should be agreed locally, in collaboration with colleagues, the responsible consultant and other local resources, ensuring the codes remain consistent with the classification principles, rules, conventions and coding standards. "

OPCS is the core coding scheme used for many datasets reporting interventions in the NHS, and underpins the English payment system for Foundation trusts. Therefore there is no precise way of recording MBCT in any national datasets, and plenty of possibilities of recording them using inappropriate codes.

The national care.data programme in England is one potential route through which reporting of mindfulness-based interventions might bear fruit. Given the prominence of mental health in the NHS strategy, it would be worth investigating further. The care.data programme is intending to provide a more holistic view of health information to support evidence-based care. However, to benefit from this it would be essential that any intervention is properly encoded in health records, and that the encoding is consistent throughout.

The other area for recording health interventions is in hospitals. There are national reports on hospital based interventions, both in-patient and out-patient. The Hospital

Episode Statistics record 125 million episodes of care a year in England. Interventions are normally recorded in the classification OPCS supported by the NHS Clinical Classifications Service. An enquiry has revealed that MBCT is not an intervention in OPCS, but there are two codes "X66.9 Other specified Cognitive behavioural Therapy" and "X66.9 Unspecified Cognitive behavioural therapy" that may be used in some circumstances to record MBCT. Some hospitals are now utilising SNOMED CT for recording of health records, and as highlighted above there is only one general term in that terminology for mindfulness-based therapies.

Conclusion

Overall, there is a degree of incompleteness and inconsistency in the different coding structures in the NHS for recording mindfulness-based interventions. This will limit the recording of MBIs, and make it difficult to track adoption. This opens up the question of what to do about it. Certainly, in the short term, trying to get the national coding systems updated to recognise MBIs properly is an important step. Also, obtaining access to the IAPT dataset for the mindfulness community would be another important step. Both of these are relatively straightforward. A more complicated step would be to look at how to uplift the recording of MBIs in the whole of the NHS and perhaps more widely into social care. The strategic step would to be to engage with the commissioning of care in the NHS, and look at ways of raising the profile of MBIs and facilitating more delivery of MBIs.

The prospect of measuring effectiveness of MBIs within the general population is contingent on recording of them, including the ability to do longitudinal studies on individuals. This is done in other areas of care, such as cancer care, and therefore it is achievable. However, there needs to be a critical mass of recording. Given that IAPT currently records about a quarter of a million referrals a year for depression (including anxiety disorders), it would only take a small percentage uptake of MBIs in that volume for statistically significant data to emerge. Given the appetite of the NHS for evidence-based data, and the existence of a feasible national data collection for tracking MBIs, there is significant potential to help with the development and implementation of MBIs.

Appendix B: Draft letter to organisation

A variant of this letter will be sent to relevant organisations and individuals.

Dear XXX

I am undertaking a research project investigating the potential of national data to support the implementation and development of Mindfulness-Based Interventions (MBIs) in the UK. I attach the research proposal.

The NHS has adopted Mindfulness Based Cognitive Therapy (MBCT) as an intervention for preventing depression relapse under certain conditions, and the research literature on mindfulness based interventions is developing fast. There is a growing interest in the use of mindfulness as an additional component of other psychological therapies within the NHS, and ongoing research is considering the broader use of mindfulness to support health and wellbeing. In addition, many major organisations are introducing mindfulness as a part of their staff development and wellbeing.

The scientific evidence base for MBIs is growing rapidly, and the interest in applying the results is developing. The Mindfulness Initiative was formed in November 2013, growing out of a programme of mindfulness teaching to Members of Parliament – so far 115 MPs and similar numbers of their staff have completed an 8 week MBCT course. There is a Mindfulness All Party Parliamentary Group, which has published a (draft) report on the potential of mindfulness in health, education, the workplace and the criminal justice system.

I would like to elicit the views of you / your organisation on what information would be of use, what relevant data currently exists, and what further developments of national data are possible. If it is of value, I would be able to provide a short seminar introducing the project and my findings to date. The results of the project will be publicly available.

Please feel free to contact me on XXXXX

Appendix C – potential stakeholder list
The following stakeholders will be considered in the research, and where possible key individuals will be interviewed. The list is provisional and likely to grow.

Mindfulness community
Bangor University - Centre for Mindfulness Research and Practice
Exeter University – Clinical Education Development and Research
Oxford University – Oxford Mindfulness Centre
University of Aberdeen
Other university centres with an interest in mindfulness
Aspire project
Action for Happiness

National Informatics
Health and Social Care Information Centre (England)
Public Health England
NHS England
Department of Health
The Welsh Assembly – health information standards
The Scottish NHS Information Standards Division
Northern Ireland NHS
Organisations with similar needs or aspirations on data, e.g. Human Fertilisation and Embryology Authority
Clinical CIO Leaders Network

Standards Organisations
Professional Records Standards Development Body
International Health Terminology Standards Development Organisation
Standardisation Committee for Care Information in Emgland
Professional bodies as appropriate (e.g. Royal College of Psychiatrists regarding mental health data, Royal College of GPs, Royal College of Physicians)

Other
The Mindfulness Exchange
Mindfulness Works
Mindful Health
Sussex Mindfulness Centre
Other NHS mindfulness initiatives