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# The Making Cases Count initiative<sup>☆</sup>

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## KEYWORDS

Routine data collection; Homeopathy; Homeopaths; Patient perspective; Stakeholders; Validated outcome measures

**Summary** Given the challenges faced, how can homeopaths communicate the power and scope of the therapeutic system of homeopathy? Homeopaths need to communicate to patients, the public and media, other healthcare professionals, healthcare researchers, and funders of healthcare (healthcare insurers, those who commission healthcare services either in publicly funded healthcare systems such as the NHS or charities).

Effective communication with these stakeholders requires information that is: (a) easily understood, (b) credible, and (c) relevant. The patient's voice is the trusted, indisputable and easily understood common ground in homeopathy. Yet, the experiences of patients are rarely heard outside the profession of homeopathy. Homeopaths are in a unique position to make these voices heard by disseminating the results of their routine practice cases incorporating their patients' voices.

The 'Making Cases Count' initiative has been created in order to bring about a culture where easily understood, trusted and salient information is regularly made available to all stakeholders in homeopathy.

The Making Cases Count initiative supports, guides and incentivises homeopaths to collect routine data with the aim of bringing about a culture where a significant proportion of homeopaths collect routine data from their patients in a format which will then be able to be transformed (i.e. anonymised, summarised and counted). This routine data requires numbers and categories to report the behavior and the perspective of patients receiving homeopathic treatment. This can be strengthened through the use of validated outcome measures in hearing patients' voices. When transformed, this routine data will then be able to inform homeopaths and more importantly other key stakeholders. It is now time to make patient cases count.

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## Background

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In many parts of the world people do not know what homeopathy can do, or what or who homeopaths can treat. "*I didn't know homeopaths could treat babies, IBS, depression, warts, etc.*"

When questioned by those interested in their services, homeopaths describe their practices either in terms of anecdotes, e.g. '*Mrs X came to see me with condition Y and Z*'

happened,' or use vague descriptions such as '*I see a lot of asthma cases*'. It is rare to hear homeopaths describe their practice in terms that are precise and easily comprehensible e.g. '*an average of 130 patients a year consult me for homeopathic treatment*'.

Though, there has been a significant amount of research into homeopathy using both observational study and experimental study designs i.e. randomised controlled trials, they fail to communicate the full scope and power of treatment by homeopaths to those who want to know.

Observational studies entail reporting information about large numbers of patients being treated by homeopaths – often in National Health Service settings and conducted by groups of homeopaths<sup>1,2</sup> or single homeopaths.<sup>3–5</sup> The results of these studies rarely reach the wider medical and research communities. Observational studies when published are often criticised for not being randomised controlled trials!

Randomised controlled trials in homeopathy are mostly (98%) placebo controlled. These trials randomly allocate trial patients to either real homeopathic medicine or a dummy/placebo. The interpretation of the results of these trials with regards to decision making about real world healthcare by homeopaths is challenging to say the least. Given the challenges faced, how can homeopaths communicate the power and scope of the therapeutic system of homeopathy?

In order to improve what is known about the work of homeopaths, a data collection initiative was designed and is currently being piloted with UK homeopaths (both professional and medical homeopaths). This article describes the methods of the data collection initiative including the target audience for the outputs of the data collection initiative, and the rationale for the type(s) of data to be collected. The results of the initiative to date are briefly described.

## Methods

The following sections describe who homeopaths need to communicate to (key stakeholders) and what they need to communicate to them, and argues that the key ingredients for effective communication includes the use of: the patient voice, numbers and categories and validated outcome measures.

**Key stakeholders** in homeopathy, i.e. groups who would benefit from a more accurate understanding of the therapeutic system of homeopathy can be grouped into four: patients, public (including the media), researchers, and healthcare providers (including homeopaths, funders of healthcare, healthcare insurers, those who commission healthcare services either in publicly funded healthcare systems such as the NHS or charities; Fig. 1).

These stakeholders require information about homeopathy that will be: (a) easily understood, (b) credible, and (c) relevant. We have identified a number of essential ingredients for effective communication.

### The patient voice

What is required is to communicate the trusted, indisputable and easily understood common ground in homeopathy is

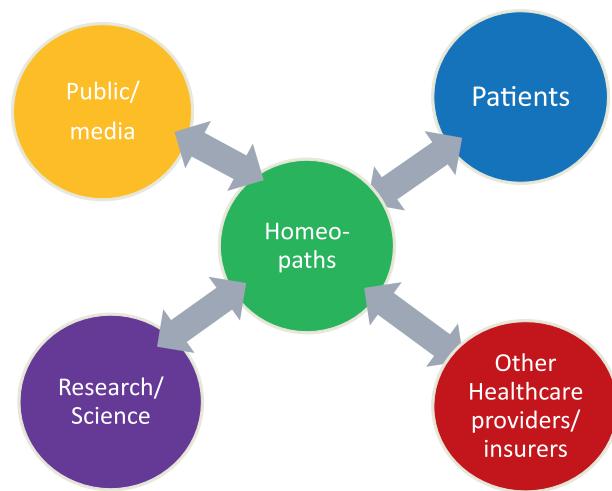


Figure 1 Key stakeholder groups in homeopathy.

the patient's voice. Knowledge about why patients seek help from homeopaths, and then what happens to them after treatment, is knowledge that anyone can relate to, regardless of their technical research skills or their beliefs regarding homeopathy.

Patient's experiences of homeopathy can be communicated in a number of ways. The media occasionally reports the story of a single patient, usually in women's magazines. Homeopaths convey patient 'cases' to other homeopaths using the single narrative style case report, specialist homeopathy language and published in the trade journals (e.g. The homeopath, Homeopathic Links, Homeopathy). These reports sometimes use selective quotes from patients, but patients' perspectives are not formally reported.

Sometimes, the profile and numbers of patients seeking homeopathic treatment is collected and published and the outcomes of these patients are also reported.<sup>1,16</sup> But given the number of patients consulting homeopaths for treatment, the number and frequency of published reports available is extremely low. The key stakeholders in homeopathy (public, healthcare professionals, funders and researchers/academics) need to hear the voices of many patients, frequently, and locally.

### Numbers and categories

The patient voice is hard to argue with, but individual voices are often inaudible. There is a need to group together the voices of patients, a way of communicating patient behaviors and experiences. Systematic collection of data on groups of patients will contribute to knowledge about patients' experiences with treatment. The voices one listens to most carefully are those that are most similar to ones own (e.g. symptom, diagnosis, geographical location, age, gender). If I have an asthmatic child in Sheffield, I will listen carefully to the voices of other mothers of asthmatic children in Sheffield.

The experiences of patients are rarely heard outside the profession of homeopathy. This means that key stakeholders (patients, public, researchers and healthcare providers) have little information upon which to base their decision

making. Homeopaths are in a unique position to make these voices heard by disseminating the results of their routine practice cases incorporating their patients' voices – and thus communicate effectively with its key stakeholders. Homeopaths have the potential to disseminate their routine practice cases – the experiences of their patients, and they must do this in a manner which all stakeholders (a) will easily understand, (b) trust, and (c) find salient.

The use of numbers and categories to report the behavior and the perspective of patients receiving homeopathic treatment can be strengthened through the use of *validated outcome measures* which help us hear the patients' voice. Any validated outcome measure could be used, but the best ones are those where the patient decides what needs to be measured and recorded – what are called 'patient generated' outcome measures. The best example of this is the outcome measure MYMOP (Measure Your Medical Outcome Profile) <http://sites.pcnd.ac.uk/mymop/index.php?c=welcome>. This is a validated outcome measure developed by Dr. Charlotte Paterson<sup>6</sup> which has been used by a number of different healthcare professionals including nurses, acupuncturists and homeopaths. Audits of homeopaths' practices which use this outcome have been published in the UK<sup>7,8</sup> and abroad (translations in Chinese, Danish, Dutch, German and Norwegian are available).

### Making cases count initiative

In order to facilitate effective communication, homeopaths and homeopathy researchers have devised the 'Making Cases Count'<sup>9</sup> initiative. This initiative aims to bring about a culture where easily understood, trusted and salient information is regularly made available to all stakeholders in homeopathy. The Making Cases Count<sup>9</sup> (MCC) initiative provides guidance and support in:

- (a) Prospectively collecting routine patient data using validated outcome measures,
- (b) Analysing the data collected,

Making this easily understood, trusted and salient information available to all stakeholders in homeopathy. All data is routine data that is collected and held by homeopaths using whatever validated outcome measure they choose. The default outcome measure is MYMOP<sup>2,10</sup>, which takes about two minutes to complete. In collecting this information from their patients, homeopaths must follow the privacy and data handling laws of their country and their professional organisation. In the pilot analysis is provided at no charge by volunteer academics and PhD students. If homeopaths seek the support of the Making Cases Count team to analyse their data, then they send anonymised data in an excel spreadsheet to the team. The team analyses this anonymised data and help the homeopaths write reports. All team members are trained researchers who use encrypted data storage methods. It is the decision of the homeopath as to how they collect this data (paper or an electronic/online database).

Homeopaths may collect clinical diagnosis codes, name and potency of homeopathic medicine, etc., however, the priority in the Making Cases Count initiative is to collect

information which quickly describes the patient (age, gender) and allows the patient voice to be heard by using their description of the symptoms for which they are seeking help.

Engaging homeopaths in collecting and reporting routine data collection is challenging,<sup>11</sup> thus the Making Cases Count initiative provides encouragement to engage in the initiative through visits to homeopathy colleges and by offering financial awards (cash) to those homeopaths who submit their anonymised information to the Making Cases Count initiative competition <http://www.makingcasescount.org/#Rewards/c170>. Competition applications will be judged on the following criteria: (i) completeness and clarity of answers to all sections in the application form, and (ii) potential for providing high quality information describing treatment by homeopaths of relevance to other healthcare professionals and/or other stakeholders in healthcare (patients, homeopaths, healthcare insurers, commissioners, policy makers, academics etc.). There have been a number of excellent plans to collect routine case data.<sup>12,13</sup> Most recently in the UK, the SoH pilot National Service Evaluation<sup>11</sup> recruited homeopaths to report on their routine practice, but numbers were low despite the efforts of the evaluation team. A number of observational studies are facilitating the reporting of routine data. Thompson et al.<sup>14</sup> piloted a process of national clinical data collection using patient-reported outcomes in homeopathic hospital outpatients with 51 UK medical homeopaths. The EvaMed project<sup>15</sup> is collecting data on patients treated with anthroposophical medicine using web-based documentation software. Though a data collection pilot, Making Cases Count differs in that the emphasis is on *facilitating* homeopaths to collect data and *providing support* for them to analyse and report the data to the audiences that they want to communicate with. Unlike Thompson et al.<sup>14</sup> and the EvaMed project<sup>15</sup> data is not centrally collected and collated, instead the data is retained and analysed by individual homeopaths.

The MCC initiative differs from previous attempts to collect routine data in that it has (i) academic support for each homeopath to collect and analyse data, and produce reports for local stakeholders and (ii) rewards for the best data collection projects. Homeopaths will be encouraged to collect information from all their consecutive cases. Homeopaths will be required to provide a range of information including: age and gender of patients, context/setting in which patients are treated (e.g. clinic, home, charity, GP practice), method of payment (e.g. privately funded, health insurance, low cost), how the patient was referred for treatment, length and cost of consultations. For the awards, applications will be assessed according to their completeness and clarity of information (guidance will be given).

### Results

With the help of a £4000 anonymous donation, the pilot of the UK Making Cases Count initiative began in 2013 with the launch of the website <http://www.makingcasescount.org/>. Information about the initiative is being disseminated to all UK homeopathy colleges and articles describing the initiative have been sent to homeopathy newsletters and journals. Research advisors at the Society of Homeopaths

provide ongoing information about the initiative to their members. Over 20 homeopaths have directly contacted the researchers and requested more information and several homeopathy colleges and associations have invited us to talk about the initiative to their students. For the best reports submitted to the Making Cases Count initiative, the anonymous donation has enabled cash awards ranging from £50 to £250 and free software packages to be offered for all entries submitted by 26th September, 2014. Four homeopaths have already sent in completed application forms (with anonymised excel spreadsheets of the data collected from their routine practices). Results of the pilot will be known in early 2015.

## Discussion

In order for routine data collection to become a common activity in the homeopathic profession, then student homeopaths would need to be trained in the use of validated outcome measures (this is happening in some UK homeopathy colleges).

The initiative has been discussed by homeopaths outside the UK through organisations such as European Central Council of homeopaths (ECCH). If the results of the UK pilot are promising then Making Cases Count is envisioned as a continuous routine data collection initiative. If funding was forthcoming then in time the initiative could be rolled out in other countries.

## Conclusions

The Making Cases Count initiative supports, guides and incentivises homeopaths to collect routine data with the aim of bringing about a culture where a significant proportion of homeopaths collect routine data from their patients in a format which will then be able to be transformed (i.e. anonymised, summarised and counted). When transformed, this routine data will then be able to inform homeopaths and more importantly inform other key stakeholders: patients, public/media, researchers and other healthcare professionals

It is now time to make patient cases count.

## Conflicts of Interest

None declared.

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