

# “Please may I have a copy of my MRI scan?”

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## Introduction

Some participants<sup>1</sup> in the Brightmind research study have asked for a copy of the images taken during their MRI scan, prompting the Lived Experience Advisory Panel (LEAP) to reflect on their possible reasons<sup>2</sup>. After we had generated some hypotheses, we reviewed some literature<sup>3</sup> and found a few more potential justifications and benefits, along with concerns expressed by those who would restrict or deny access. These ideas are presented in the hope that they will stimulate, first, a more person-centred discussion about return of health data in general, and second, some serious investigation into what motivates research participants and patients to ask for their MRI scan in particular.

The ideas from the LEAP form the structure for this paper, augmented with a few ideas that emerged from the literature<sup>4</sup> and a discussion of each potential motive is begun under each heading. Topics overlap and combine in a variety of ways, and we anticipate that some would be freely volunteered by participants, while others might only emerge as support for an idea suggested by someone else. Particular note is taken of the coproduced recommendations generated by Cook et al<sup>5</sup> as patients were active partners, in line with the ethos driving Brightmind.

## A. Just for me

### A1. To exercise my rights

**Many people would like a copy of the scan images.** The small proportion of people who actually ask for a copy of their scan image is not representative of the proportion that want one. Shoemaker et

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<sup>1</sup> Brightmind researchers estimate that by April 2020, around 25 participants had made this request. As a result, an application will be submitted for permission from the Research Ethics Committee to explore this question in more detail.

<sup>2</sup> Comments have been received from the following members of the Brightmind LEAP: John Gledhill, Mark Liddell, Rebecca McNaughton, Bev Smith, Sarah Wilkinson and Andy Willis.

<sup>3</sup> A search of Google Scholar was carried out using the Search term 'Patient Experience MRI' and set to 2020. The first 300 items were considered and any titles that appeared relevant were then followed to review the abstract and perhaps the full text, if available in Open Access via Google Scholar or Unpaywall). If the full text was not available, the abstract looked relevant and the email address of the corresponding author was available, a standard email was then sent out requesting help. This exercise was repeated for publications from 2019 and 2018. When a full text was reviewed, some relevant citations were followed up. Responses were received from David Carpenter, Amber Liles, Ben Parkinson and Carla Semedo. The contents of this paper are entirely the responsibility of the authors. Limitations of this review include (i) Paywalled papers and papers older than 2018 were not included in the initial trawl; (ii) nothing has been yet found that represents the guidance of professional bodies; (iii) no systematic approach was used for assessing the content of the papers that were accessed; (iv) almost all papers considered their material from the perspective of health professionals, so their remarks have been reframed in this paper to tease out potential patient perspectives; (v) the traditional IMRaD format for academic papers is not used.

<sup>4</sup> While there is some literature, as indicated in these endnotes, the bulk of research into patient experience and MRI appears to focus on (i) reducing discomfort whilst in the scanner, to improve the quality of the image and minimise withdrawal for the scan process; (ii) managing incidental findings rather than normal scans; and (iii) responding to clinically significant scans rather than abnormal findings that are considered to have no clinical significance.

<sup>5</sup> Cook TS, Krishnaraj A, Willis MH, Abbott C, Rawson JV, (2016) An Asynchronous Online Collaboration Between Radiologists and Patients: Harnessing the Power of Informatics to Design the Ideal Patient Portal *Journal of the American College of Radiology*, Volume 13, Issue 12, 1599 – 1602.

al<sup>6</sup> found that '87% of research participants expressed a preference to receive all scan findings.' Other studies have obtained similar findings that patients want access to their scan image and not just radiology reports<sup>7</sup>. In a survey of 130,000 patients<sup>8</sup>, half of the group with radiology reports chose to access them, compared with only a third who wished to see other medical notes. In another study reporting on the preferences of over 600 radiology patients, two thirds wanted a copy of their radiology report and 85% wanted a copy of the actual images<sup>9</sup>. Greco and colleagues<sup>10</sup> obtained feedback from 500 patients who accessed scan images and 96% responded favourably. There is a similar interest in other healthcare fields<sup>11</sup>.

These studies point to the importance of a clear typology of the different kinds of feedback that the person might receive, including (i) the original MRI images in DICOM format which require specialist viewing software<sup>12</sup>; (ii) the images compressed into jpg format, which means that detail, brightness and contrast is lost, rendering them of little clinical value; to (iii) a hard copy of selected images, as there can be more than 100 in an MRI series. In general, there seems to be a growing appetite amongst patients for raw data<sup>13</sup>, which then brings in the question of encryption. Any images which are transferred within the health system will be encrypted so that they are effectively anonymised and cannot be viewed unless the password is also supplied. Suitable arrangements for the provision of scan data in electronic formats need to be clear.

but people may also wish to receive a copy of the formal technical narrative report on the conclusions drawn from the data, a lay summary, and finally a wider story of disease and treatment.

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<sup>6</sup> Shoemaker JM, Cole C, Petree LE, Helitzer DL, Holdsworth MT, Gluck JP & Phillips JP (2016) Evolution of universal review and disclosure of MRI reports to research participants *Brain and Behavior*, 2016; 6(3), e00428. Available at <https://onlinelibrary.wiley.com/doi/full/10.1002/brb3.428>

<sup>7</sup> See Cabarrus M, Naeger DM, Rybkin A, Qayyum A (2015) Patients prefer results from the ordering provider and access to their radiology reports. *J Am Coll Radiol* 12(6):556–562. Available at <https://escholarship.org/content/qt60h041kb/qt60h041kb.pdf?t=ny0llk>. Also Lee CI, Langlotz CP, Elmore JG (2016) Implications of direct patient online access to radiology reports through patient web portals. *J Am Coll Radiol* 13(12 Pt B): 1608–1614. Also Johnson AJ, Frankel RM, Williams LS, Glover S, Easterling D (2010) Patient access to radiology reports: what do physicians think? *J Am Coll Radiol* 7(4):281–289. Also Kirschen MP, Jaworska A, Illes J. Subjects' expectations in neuroimaging research. *J Magn Reson Imaging* 2006; 23:205–209.

<sup>8</sup> Miles RC, Daniel S, Hippe DS, Elmore JG, Wang CL, Payne TH, Lee CI (2016) Patient Access to Online Radiology Reports: Frequency and Sociodemographic Characteristics Associated with Use *Academic Radiology* Volume 23, Issue 9, September, Pages 1162-1169. <https://doi.org/10.1016/j.acra.2016.05.005>

<sup>9</sup> Cabarrus et al (2015) op cit.

<sup>10</sup> Greco G, Patel AS, Lewis SC, Shi W, Rasul R, Torosyan M, Erickson BJ, Hiremath A, Moskowitz AJ, Tellis WM, Siegel EL, Arenson RL, Mendelson DS (2016) Patient-directed Internet-based Medical Image Exchange:: Experience from an Initial Multicenter Implementation *Academic Radiology* Volume 23, Issue 2, February, Pages 237-244. <https://doi.org/10.1016/j.acra.2015.10.012>

<sup>11</sup> Middleton's team asked 4140 participants in a genome study about their raw data and 61% wanted access to it. Middleton A, Wright CF, Morley KI, Bragin E, Firth HV, Hurlles ME, et al (2015) Potential research participants support the return of raw sequence data. *J. Med. Genet.* 52:571–74.

<sup>12</sup> Mirada Medical sell software that enables the user to view and compare DICOM compatible images, as do Conquest (at <https://ingenium.home.xs4all.nl/dicom.html>). Conquest can receive, send, manipulate and store images, and includes a simple viewer. A simple, free DICOM image viewer can be found at <http://www.microdicom.com/>.

<sup>13</sup> See the example of genomic data – see Evans BJ, Dorschner MO, Burke W, & Jarvik GP (2014) Regulatory changes raise troubling questions for genomic testing, *Genet Med.* November; 16(11): 799–803. doi:10.1038/gim.2014.127.

In addition to asking for some or all of these documents, the person may be asking for a discussion about its meaning, of which more below.

**The law underpins entitlement.** In law and privacy regulations<sup>14</sup>, images count as personal data and participants have a right to them. Unfortunately, not everyone understands this. Lye et al<sup>15</sup> checked out the practice of 80 top US hospitals and found two that refused patient access to MRI scans on the grounds that they believed that images could only be provided to healthcare professionals and not to patients. Others may fear that, should the person mislay the images, the scanning service would be blamed for the data breach. Despite these concerns, citizens generally have a right to know what is being recorded about them, view the contents, amend or delete them and control their distribution and destruction.

Brain scans are as unique as fingerprints, and so even anonymised scans stripped of patient names and other identifying text can in theory be re-identified<sup>16</sup>, so count as personal data. In an age of social media, big data and identity theft it is especially important that people retain these rights to limit the ability of others to re-identify anonymised data, release confidential material into the public domain or share them with other agencies including public health and research bodies.

**No need to say why.** Simply asking for a copy of the scan image should be sufficient reason to provide it, and no further explanation should be required. Several LEAP members considered that the rights argument was particularly important.

## A2. To reclaim power as an active partner in my treatment

**To combat paternalism.** Citizens who become patients or research participants enter a power relationship where they subject themselves to the will of professionals, while at the same time those same professionals seek to empower the person to disclose their perceptions, take ownership of their health status and fulfil their part of the bargain. This is a tricky balance to achieve, and, in the past, many researchers and clinicians took a paternalistic approach, attempting to protect participants from the harm that might come from seeing their scan image, misunderstanding it or misusing it<sup>17</sup>. After undergoing an MRI scan, the person may wish to reduce the power imbalance a

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<sup>14</sup> In America, this is the Health Insurance Portability and Accountability Act Privacy Rules -see 45 CFR [Part 160](#) and Subparts A and E of [Part 164](#). In Europe and the UK, this is the General Data Protection Regulation (GDPR), enshrined in the Data Protection Act 2018. There is also a long history of patient access to medical records, of which access to MRI scan images and the reports written by radiologists and communicated via online patient portals is no more than the most recent manifestation. The debates surrounding this practice are well articulated, although a distinction may be needed to separate the practice of providing patients with a copy of the record from the practice of asking to patient to become the repository, in which case the records is described as 'patient held', rather than kept by the institution.

<sup>15</sup> Lye CT, Krumholz HM, Eckroate JE, Daniel JG, deBronkart D, Mann MK, Hsiao AL, Forman HP (2019) Evaluation of the patient request process for radiology imaging in U.S. hospitals *Radiology* 292:409–413. <https://doi.org/10.1148/radiol.2019190473>.

<sup>16</sup> A full head brain scan, rendered in 3D, might be recognised by someone who knew the person. There are other reasons too that scan data could be re-identified, at least in theory – see Valizadeh SA, Liem F, Méryllat S, Hänggi J & Jäncke L (2018) Identification of individual subjects on the basis of their brain anatomical features *Nature* 8:5611. Available at <https://www.nature.com/articles/s41598-018-23696-6.pdf>

<sup>17</sup> In the case of people with Alzheimer's Disease, paternalism was found and concerns were raised about the ability of the person to understand the information that was provided – see <http://europepmc.org/backend/ptpmcrender.fcgi?accid=PMC3795601&blobtype=pdf>. There are other rights-based reasons for patients to have more control of the processes that they go through. For example, cardiac patients are 50 times less likely than others to be offered an MRI, despite the fact that the earlier technical

little by seeing the output and then taking an active part in discussions and decisions about what it means and what to do.

**To promote autonomy.** Johnson et al<sup>18</sup> note that providing access to the scan findings is likely to enhance the person's sense of autonomy and therefore increase their knowledge and understanding of their health status, endorse treatment and take more responsibility for their own health.

### A3. To understand and accept my illness

**To be well informed.** Most people benefit from understanding the purpose of tests, the name of their illness<sup>19</sup>, the normal course of its progression and the nature and effect of interventions. Some may ask for a copy of the scan as a veiled request for this broader information, perhaps because they lack even basic facts about their prognosis. Even where the patient does not want to understand these things, it should be their choice to decline the information rather than others who deny access to it.

The term health literacy refers to the person's knowledge of their body, the illness and treatments as well as ability to understand information that is provided and use it well. Shoemaker's team<sup>20</sup> found that staff took a much more pessimistic view of participants' health literacy levels than the people held about themselves. The OpenNotes team<sup>21</sup> were pleasantly surprised at the high level of comprehension demonstrated by patients who read their medical notes, although this finding may not be replicated in the specific case of MRI scan reports. Questions remained outstanding about the person's actual health literacy rather than their self-perception of it, and the level of readability of the scan report.

**To receive information in an accessible format.** Root et al<sup>22</sup> found only 3% of their sample of over 4,000 patients who looked at their health records found the information confusing, and those who did tended to be older, unemployed and less well educated. Some participants ask for the MRI report to be presented in accessible lay language rather than technical jargon<sup>23</sup>, others want the technical material in its entirety<sup>24</sup>, and yet more advocate providing interpretation along with the

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problems about safe scanning for this group have been solved – see <https://link.springer.com/article/10.1007/s00330-019-06449-5>

<sup>18</sup> Johnson et al (2010) op cit.

<sup>19</sup> This paper sometimes uses the term 'illness', despite its association with individualistic medical frameworks rather than biopsychosocial approaches. This is to strengthen the application of the ideas in this paper with other fields beyond mental health care.

<sup>20</sup> Shoemaker et al (2016) op cit.

<sup>21</sup> Delbanco T, Walker J, Bell SK, Darer JD, Elmore JG, Farag N, et al (2012) Inviting patients to read their doctors' notes: A quasi-experimental study and a look ahead. *Ann Intern Med American College of Physicians*; Oct 2;157(7):461–470.

<sup>22</sup> Root J, Oster NV, Jackson SL, Mejilla R, Walker J, Elmore JG (2016) Characteristics of patients who report confusion after reading their Primary Care clinic notes online. *Health Commun.* 2016;31(6):778-81. doi: 10.1080/10410236.2014.990078.

<sup>23</sup> Gunn A, Mangano M, Sahani D, Boland G, Choy G (2014) Structured feedback from patients on actual radiology reports: a novel approach to improve reporting *practices Proc. Radiological Society of North America Scientific Assembly and Annual Meeting: Chicago, IL*, . Available at: <http://archive.rsna.org/2014/14011827.html>. Also Johnson et al (2010) op cit.

<sup>24</sup> See Henshaw D, Okawa G, Ching K, Garrido T, Qian H, Tsai J. (2015) Access to radiology reports via an online patient portal: Experiences of referring physicians and patients. *J Am Coll Radiol.* Jun;12(6):582-6.e1. doi: 10.1016/j.jacr.2015.01.015. Also Mangano MD, Rahman A, Choy G, Sahani DV, Boland GW, Gunn AJ. (2014) Radiologists' role in the communication of imaging examination results to patients: perceptions and

report, to mitigate misunderstandings and anxiety<sup>25</sup>. There is evidence to suggest that family doctors also benefit from receiving clear, straightforward statements in the report<sup>26</sup>.

Members of the physicians focus group convened by Johnson et al<sup>27</sup> noted that a phone or face-to-face conversation between the radiologist and the doctor elicited far more useful information than the abbreviated summary that found its way on to the written report. Shoemaker's team<sup>28</sup> negotiated with researchers to identify a relatively small number of potential outcome categories that arose from scan findings and to generate template reports and summary letters<sup>29</sup>. This helped radiographers to be clear about the key message that needed to be given to the person and streamlined the process. At its heart was the clear binary recommendation to either discuss the scan with their doctor or that there was no need to do so.

Radiologist's reports tend to use a lot of technical terminology. For example, Oh's team<sup>30</sup> examined the reports written by radiologists following an MRI scan of the knee and found a median of 75 terms that needed explanation. This obviously creates the potential that the report will be misunderstood by the lay person who reads it. Perhaps writing an accessible report for the person will 'dumb-down' the clinical utility of the radiologist's narrative report, making it less useful for professional readers, or hide essential clinical information in lengthy explanations for lay persons which simply will not be read by busy clinicians. Shoemaker et al<sup>31</sup> found that a simple lay summary which directed the person to see their doctor or indicated clearly that there was no need to seek further medical advice tended to allay anxiety. In contrast, the focus groups convened by Johnson et al<sup>32</sup> did not favour limiting the feedback to the person to just this statement, rather, it should appear as a summary of a longer description of findings.

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preferences of patients *American Journal of Roentgenology* Nov;203(5):1034-9. doi: 10.2214/AJR.14.12470. Also Cabarrus et al (2015) op cit.

<sup>25</sup> Pillemer F, Price RA, Paone S, Martich GD, Albert S, Haidari L, Updike G, Rudin R, Liu D, Mehrotra A (2016) Direct release of test results to patients increases patient engagement and utilization of care. *PLoS One*. Jun 23;11(6):e0154743. doi: 10.1371/journal.pone.0154743.

<sup>26</sup> McCullough BJ, Johnson GR, Martin BI & Jarvik JG (2012) Lumbar MR imaging and reporting epidemiology: do epidemiologic data in reports affect clinical management? *Radiology*, 262, 941-6.

<sup>27</sup> Johnson et al (2010) op cit.

<sup>28</sup> Shoemaker et al (2016) op cit.

<sup>29</sup> Cook et al (2016) op cit note that specialities vary in their culture, so, for example, it is a requirement under the Mammography Quality Standards Act (MQSA) to provide a lay summary for the patient as well as a technical report for clinicians, and patients can obtain the original mammogram if they wish. These practices have not often been adopted in other sub-specialties of radiology. Effective use of templates has potential benefits of providing a checklist to ensure that all issues are covered; saving time otherwise spent in creating a structure for each report; and scrutiny of the individual words, phrases and sentences that are chosen, thereby enhancing clarity and helping readers to navigate the report. The downside is that template reports can be less personalised to the individual, and authors may create risk-averse, cautionary text that fails to communicate potentially useful material. See Marcovici PA & Taylor GA (2014) Journal Club: Structured radiology reports are more complete and more effective than unstructured reports *American Journal of Roentgenology*. Vol 203, No 6, pp 1265-1271. DOI: 10.2214/AJR.14.12636

<sup>30</sup> Oh et al (2016) op cit.

<sup>31</sup> Shoemaker et al (2016) op cit.

<sup>32</sup> Johnson et al (2010) op cit.

Shoemaker's team<sup>33</sup> also planned to add some targeted educational material with the scan report and cover letter to help with health literacy<sup>34</sup>, while Oh and colleagues<sup>35</sup> have added illustrations of concepts and accessible definitions to the technical report. Broader educational material for patients about radiology is available<sup>36</sup>, but this not related to an individual patient or scan. Johnson et al<sup>37</sup> note that, if high-quality educational resources are not provided, people will seek their own, and this may result in people drawing on inaccurate or unwise material. Kole and Fiester<sup>38</sup> recommend that education is provided prior to the scan too, as this validates the consent process, and that radiologists are the most appropriately trained people to undertake the consent discussion with the person. People who receive a copy of their scan image need to understand the what this document signifies.

**To receive information in an acceptable way.** There are communication challenges when the medical information is technical and time is short, and when the person lacks knowledge, academic training, ability to understand and concentration. In exceptional circumstances, access to information can be denied by professionals in order to prevent the harm that would occur should it be released, but the threshold is fairly high – it must be imminent and serious harm to physical or mental health, not trivial risks<sup>39</sup>. In almost all circumstances, people consider the truth to be their friend, and finding out the results of an MRI scan can help them to accept their health status. As one LEAP member described it, the scan might 'help me to see that my brain is wired differently to others', helping the person to build a personal explanation to help with psychological adjustment.

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<sup>33</sup> Shoemaker et al (2016) op cit.

<sup>34</sup> This recommendation is also made by Powell DK (2014) Patient explanation guidelines for incidentalomas: helping patients not to fear the delayed surveillance. *American Journal of Roentgenology* 202(6):W602. Available at <https://www.ajronline.org/doi/full/10.2214/AJR.13.12337>. Meanwhile McCormick JB, Sharp RR, Farrugia G, et al (2014) Genomic medicine and incidental findings: balancing actionability and patient autonomy. *Mayo Clin Proc.* 89(6):718–21 prompt the idea that decision support tools may assist patients to select what action they want to take in response to the scan findings.

<sup>35</sup> A prototype called PORTER begins with provision to upload a radiology report to its database. It then provides a glossary of terms and an online view of the report with annotations and illustrations that appear in a balloon on the screen when the person hovers over individual words. Oh SC, Cook TS, & Kahn CE. (2016) PORTER: A prototype system for patient-oriented radiology reporting *J Digit Imaging.* Aug; 29(4): 450–454. DOI 10.1007/s10278-016-9864-2. Similarly, efforts have been made to simplify the lexicon of technical terms used in radiology reports so that lay persons can understand their content more easily. See Qenam B, Kim TY, Carroll MJ, & Hogarth M (2017) Text simplification using consumer health vocabulary to generate patient-centered radiology reporting: Translation and evaluation. *J Med Internet Res.* Dec 18;19(12):e417. DOI:10.2196/jmir.8536.

<sup>36</sup> See <https://www.radiologyinfo.org/> and the glossary of terms at <https://www.radiologyinfo.org/en/glossary/browse-glossary.cfm?term=A>. However, one study suggested that it's terms remain obscure to many patients – see Hansberry DR, John A, John E, Agarwal N, Gonzales SF, Baker SR (2014) A critical review of the readability of online patient education resources from RadiologyInfo.Org. *AJR Am J Roentgenol* 202: 566–575. An alternative glossary can be found at [www.RadiologyExplained.com](http://www.RadiologyExplained.com). Oh and colleagues note that it is reasonable to assume that patients would also want lay explanations of disease, imaging technology and medical procedures - see Oh et al (2016) op cit..

<sup>37</sup> Johnson et al (2010) op cit.

<sup>38</sup> See Kole J, Fiester A (2013). Incidental findings and the need for a revised informed consent process. *American Journal of Roentgenology* 201(5): 1064–8.

<sup>39</sup> Thorogood A, Bobe J, Prainsack B, Middleton A, Scott E, Nelson S, Corpas M, Bonhomme N, Rodriguez LL, Murtagh M, Kleiderman E and on behalf of the Participant Values Task Team of the Global Alliance for Genomics and Health (2018) APPLaUD: Access for patients and participants to individual level uninterpreted genomic data, *Hum. Genomics* 12:7. <https://doi.org/10.1186/s40246-018-0139-5>.

#### A4. To understand the interaction with other conditions and experiences

**To help me choose a healthy lifestyle.** Seeing the evidence from the scan may help me make some decisions in other parts of my life, such as slowing down or spending more time with the people I love.

**To manage comorbidities.** Many people live with multiple comorbidities and so have to navigate the interplay between them as well as each individual condition. While on occasions there is clear evidence about how one condition will affect other, seemingly disconnected parts of the body, emotions or behaviour, some people live with considerable uncertainty. This amplifies the amount of guesswork and experimentation required of both the person themselves and the health professionals who treat and support them.

**To accept ambiguity.** We can expect some people to respond by searching for certainty, and this may drive their wish to see their scan images, perhaps fuelling demands for visible stigmata on the scan and an accompanying unambiguous diagnosis. But most people are familiar with uncertainty, and this is particularly helpful for reading MRI scans, as findings are often ambiguous and the scan image suggests possible futures only in the most tentative manner. Indeed, attempts to test inter-rater reliability by asking different radiologists to assess the same findings have yielded mixed results<sup>40</sup>, adding a further layer of ambiguity to scan reports. All this means that health professionals need considerable skill in conveying ambiguity<sup>41</sup>.

**To hold on to an anchor.** For people who are depressed, there may be acute feelings of depersonalisation (loss of the sense that one's inner life is real) or derealisation (loss of connection with the external world), and either of these may drive people to collect evidence that helps to verify that they themselves and their depression are genuine experiences. Holding a physical copy of the scan image may act as a bulwark against such feelings.

#### A5. To receive an early warning of upcoming problems

**To benefit from a health check.** Whilst uncertainty is a common output from an MRI scan, there are occasions when the scan reveals medically significant findings that were either asymptomatic or that explain previously undiagnosed issues that have hitherto been unreported. A scan may reveal the presence of a tumour or other threat. Studies have found that up to a third of scans reveal incidental findings unrelated to the purpose of the research<sup>42</sup> and these can be sent to a qualified person for

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<sup>40</sup> Herzog et al sent the same patient to 10 radiology services for a MRI scan of her lower back. The results showed a damning level of inconsistency – see Herzog R, Elgort DR, Flanders AE, Moley PJ (2017) Variability in diagnostic error rates of 10 MRI centers performing lumbar spine MRI examinations on the same patient within a 3-week period. *Spine J.* 2017 Apr;17(4):554-561. doi: 10.1016/j.spinee.2016.11.009. The matter was retrieved somewhat by Doktor K, Jensen TS, Christensen HW, Fredberg U, Kindt M, Boyle E, Hartvigsen J (2020) Degenerative findings in lumbar spine MRI: an inter-rater reliability study involving three raters. *Chiropr Man Therap.* 2020 Feb 11;28(1):8. doi: 10.1186/s12998-020-0297-0. Brains might be easier to read than spines.

<sup>41</sup> Bruno MA, Petscavage-Thomas J, & Abujudeh HH (2017) Communicating Uncertainty in the Radiology Report *American Journal of Roentgenology* 2017 209:5, 1006-1008

<sup>42</sup> Shoemaker et al 2016 op cit.



clinical interpretation. A small proportion of these have health or reproductive consequences that may benefit from intervention<sup>43</sup>, and a handful require an urgent response<sup>44</sup>.

**To consider this before consenting.** Both researchers and clinicians have both a duty of care<sup>45</sup> and a 'duty to warn'<sup>46</sup>. International guidance<sup>47</sup> directs researchers to include discussions about the potential of incidental findings in the consent process, in contrast with some clinical practice that is less thorough in this regard<sup>48</sup>. Weiner and colleagues<sup>49</sup> advised that discussions should take place with the person prior to scanning to ascertain their preferences in terms of the reporting back of incidental findings, and that researchers bear a responsibility and must ensure that the person does get to hear about any findings that have serious repercussions. In this context, the research world overlaps with the clinical world, with their different cultures around consent, and so clarity is especially important<sup>50</sup>.

**To engage with the right professional discipline.** There may be quite a long chain of communication from the researcher-led MRI scan to the rare occasion when clinically significant findings are found which need to be discussed with the person. This involves the following steps:

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<sup>43</sup> Bos D, Poels MM, Adams HH. Prevalence, clinical management, and natural course of incidental findings on brain MR images: the population-based Rotterdam Scan Study. *Radiology*. 2016; 281:507. Available from <https://pubs.rsna.org/doi/pdf/10.1148/radiol.2016160218>.

<sup>44</sup> Clayton argues that incidental findings should only be disclosed to the person if they have a high value in terms of their ability to drive health benefit. See Clayton EW. Incidental findings in genetics research using archived DNA. *J Law Med Ethics*. 2008;36(2):286–212. Available at <http://europepmc.org/backend/ptpmcrender.fcgi?accid=PMC2576744&blobtype=pdf>.

<sup>45</sup> See [https://www.cell.com/neuron/fulltext/S0896-6273\(20\)30068-4?returnURL=https%3A%2F%2Flinkinghub.elsevier.com%2Fretrieve%2Fpii%2FS0896627320300684%3Fshowall%3Dtrue](https://www.cell.com/neuron/fulltext/S0896-6273(20)30068-4?returnURL=https%3A%2F%2Flinkinghub.elsevier.com%2Fretrieve%2Fpii%2FS0896627320300684%3Fshowall%3Dtrue)

<sup>46</sup> Evans, BJ & Wolf SM (2019) A Faustian bargain that undermines research participants' privacy rights and return of results *Florida Law Review* Vol 71, pp1281-1345.

<sup>47</sup> Note that these international guidelines related to CT scans while involve ionizing radiation, so their use may increase cancer risk which may sharpen up the attention to the consent process, in contrast with MRI where the risk is lower and so professionals may be less assiduous. See Council for International Organizations of Medical Sciences website. Council for International Organizations of Medical Sciences; World Health Organization. International ethical guidelines for biomedical research involving human subjects. [www.cioms.ch/publications/layout\\_guide2002.pdf](http://www.cioms.ch/publications/layout_guide2002.pdf). Published 2002.

16. Illes J, Kirschen MP, Edwards E, et al. (2006) Incidental findings in brain imaging research: what should happen when a researcher sees a potential health problem in a brain scan from a research subject? *Science* 311:783–784

<sup>48</sup> Lee CI, Flaster HV, Haims AH, Monaco EP, Forman HP (2006) Diagnostic CT scans: institutional informed consent guidelines and practices at academic medical centers. *AJR*; 187:282–287.

<sup>49</sup> Weiner C. Anticipate and communicate: ethical management of incidental and secondary findings in the clinical, research, and direct-to-consumer contexts (December 2013 report of the Presidential Commission for the Study of Bioethical Issues). *Am J Epidemiol*. 2014;180(6):562–4.

<sup>50</sup> Kole & Fiester (2013) op cit explain that the term 'informed consent' is sometimes used in the context of gaining permission to act, so that, for example, surgery is carried out appropriately rather than being considered grievous bodily harm. In other situations, the phrase refers to what are core principles enshrined in the Mental Capacity Act – understanding alternative courses of action and their likely consequences, weighing up options, coming to a decision and communicating that decision to another.

- (i) the research must consider this screening to be part of their role, in line with established procedures findings<sup>51</sup>
- (ii) conduct a scan of the type that will yield clinically useful findings or trigger one. There are different kinds of MRI scan, varying by their target, degree of contrast, resolution and process, so, for example, T1 is sufficient for some research while a T2 or FLAIR inversion scanning is more effective for spotting lesions and so is more clinically useful. The person who has received a research-grade scan may mistakenly think that this has produced clinical-grade results of use to their medical team in diagnosis or treatment.
- (iii) have a consistent method of selecting the images that are sent to a radiographer<sup>52</sup>
- (iv) ensure any clinical implications that may be evident from the scan are identified and addressed in a timely fashion<sup>53</sup>
- (v) arrange for the results of this interpretation to be reported to the patient<sup>54</sup>
- (vi) fast-track the process when clinically urgent matters are identified.

This means that the person may request a copy of the scan and receive feedback from the researcher, who informs the person that they wish to seek further advice but may not have much clinical expertise; from the radiographer, who has expertise in reading the scan but may not have been told why the scan was requested<sup>55</sup>; from a neurologist, who can advise on specialist treatment but may not have access to the person's medical history; or from the person's General Practitioner, who has the long-term relationship with the person and their household<sup>56</sup>. Unless there is a clear system for submitting and responding the request for a copy of the scan, it is possible that it will get lost or passed from one busy employee to another rather than actioned.

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<sup>51</sup> See <https://www.ncbi.nlm.nih.gov/pubmed/18547191>. Also <https://www.cambridge.org/core/services/aop-cambridge-core/content/view/9639C1BCDD5EDC248BCEFD26B35EE9FD/S0317167118003979a.pdf/div-class-title-identaloma-discoveries-in-the-course-of-neuroimaging-research-div.pdf>

<sup>52</sup> From a Canadian perspective, Stip and colleagues remark that few researchers who conduct functional MRI have sufficient skill to give a clinical interpretation of an MRI scan themselves. Consequently, they recommend that researchers should receive at least 50 hours of training from a professor in neuroradiology prior to deciding which images to refer for clinical assessment. See Stip E, Miron J-P, Nolin M, Letourneau G, Bernazzani O, Chamelian L, Boileau B, Gupta M, Luck D, Lungu O (2019) Incidentaloma discoveries in the course of neuroimaging research *Can J Neurol Sci* 46: 275–279. doi:10.1017/cjn.2018.397.

<sup>53</sup> Stip et al (2019) op cit note that researchers may not review the data until months or years after the MRI scan has been undertaken, and this timing is not suitable when there are clinical implications.

<sup>54</sup> Ells C, Thombs BD (2014) The ethics of how to manage incidental findings. *CMAJ*. 186(9):655–6.

<sup>55</sup> Johnson et al (2010) op cit.

<sup>56</sup> The question of which professional should provide feedback to the patient is discussed by Smith JN & Gunderman RB (2010) Should we inform patients of radiology results? *Radiology* 255:317–321. DOI:10.1148/radiol.10091608. Kole and Fiester (2013) op cit argue that a radiologist should always be the person to provide the feedback, as they have the most relevant knowledge. As we might imagine that radiologists have traditionally enjoyed less direct patient contact and therefore may have fewer skills in communication and empathy, Stip et al (2019) op cit recommend that the report written by the radiologist should be sent to a neurologist, who should offer the follow-up appointment and discussion with the person. A third option is provided by Johnson et al (2010) op cit, suggesting that the person's family doctor has access to a broader understanding of the person's medical history, social circumstances, relationship with healthcare and so on, which means that they are the most appropriate professional to help the person understand the scan findings. The family doctor will also be more adept at explaining treatment options in response to treatable abnormalities. A fourth option is for the 'referring physician' who asked for the scan to be done in the first place, to discuss its findings with the person.

**To get the facts.** Shoemaker and colleagues<sup>57</sup> found that the vast majority of patients wanted to receive feedback about their scan, irrespective of whether it contained incidental findings or not.

#### A6. To be reassured that I do not have other illnesses

**To reduce demand for unwarranted interventions.** There are occasions when medical tests and interventions are used inappropriately, with GPs and patients colluding to obtain antibiotics and sometimes even MRI scans in spite of the evidence to the contrary<sup>58</sup>. Some authors have suggested that disclosure of incidental findings will increase demand for health services as well as triggering painful and risky biopsies and other investigations, (Kole and Fiester<sup>59</sup>; Stip et al<sup>60</sup>).

In contrast to these opinions, McCullough<sup>61</sup> and colleagues investigated the effect of inserting a simple statement into appropriate reports for MRI scans of people with low back pain, indicating that scan abnormalities were common in the general population and were not, in themselves, indicative of back pain. Including the statement was associated with less frequent prescription of narcotic medication, potentially saving money and reducing the risk of dangerous side effects of this medication. Providing good information to help the person and their family doctor understand the significance of the scan is more likely to reduce rather than increase the demand for unwarranted interventions.

**To dismiss groundless fears.** In the same way as nature abhors a vacuum, some people are prone to fears and phantasies that crowd in to fill a space devoid of information. Evidence from the OpenNotes programme<sup>62</sup> shows that, for the majority of patients, being kept in the dark is anxiety-provoking, so having early access to the findings leads to a reduction in anxiety, and permits people to respond to bad news at home with their loved ones around them, prepare emotionally and distil useful questions to bring to the appointment with their doctor.

**To reduce anxiety.** Disclosure of incidental findings can be delivered badly, leaving the person with false reassurance and storing up psychological distress for the future, but, if done well, while it may lead to some short-term distress, there is a longer-term benefit. Alternatively, staff may assume that the person is experiencing a much greater level of anxiety than is in fact the case. Kole and Fiester<sup>63</sup> anticipate that some patients, given worrying news about an incidental finding but not yet having the opportunity to see their doctor, may reframe any trivial twinge as evidence of disease, leading to a spike in health anxiety as well as fear of disease, treatment and death.

Shoemaker's team<sup>64</sup> found a difference between staff assumptions and actual patient experience, with clinical staff assuming that the person receiving their MRI report would experience a high level of anxiety, while the actual level reported by the person was significantly lower. It might be

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<sup>57</sup> See Shoemaker et al (2016) op cit.

<sup>58</sup> However, Alhowimel's research into non-specific back pain found that the patients who had received an MRI were more likely to experience negative changes – an increase in their level of fear regarding potential deterioration and increased anxiety in relation to this. See [https://www.researchgate.net/publication/334587726\\_Psychosocial\\_factors\\_associated\\_with\\_an\\_MRI\\_diagnosis\\_of\\_chronic\\_non-specific\\_low\\_back\\_pain\\_in\\_Saudi\\_Arabia](https://www.researchgate.net/publication/334587726_Psychosocial_factors_associated_with_an_MRI_diagnosis_of_chronic_non-specific_low_back_pain_in_Saudi_Arabia)

<sup>59</sup> See Kole and Fiester (2013) op cit

<sup>60</sup> See Stip et al (2019) op cit.

<sup>61</sup> McCullough et al (2012) op cit. BJ,

<sup>62</sup> Delbanco et al (2012) op cit.

<sup>63</sup> See Kole and Fiester (2013) op cit.

<sup>64</sup> Shoemaker et al (2016) op cit.

suggested that the authors of some academic papers in the field suffer from a similar misapprehension and assume that the person will have a myriad of negative responses to feedback without deigning to investigate. In contrast, Phillips et al 2015<sup>65</sup> support complete disclosure of MRI scan results.

**To support people who lack mental capacity.** Researchers that investigate the impact of providing MRI scan images on patients' wellbeing, health anxiety or consumption of healthcare are perforce investigating a secondary, rather than a primary matter. Reducing public expenditure, fear and anxiety are worthwhile targets, but if these efforts fail, the primary task remains, which is to uphold people's rights to access their entire health record. Rather, the debate shifts to a second issue, which is to ensure that the patient is fully informed about the potential for benefit or harm and is then supported to make their own decision about whether to receive their own information or not. After this, a third issue comes into focus, which is then to provide advocacy support and appoint an independent decision maker to act in the best interests of those people who lack the mental capacity to exercise that choice on their own account<sup>66</sup>.

The Mental Capacity Act 2005 also secures the right of people who have mental capacity to make unwise decisions. So one might hope that providing a copy of the scan does not cause distress or lead to the person refusing vital treatment, but if it is clearly the person's wish to see the findings and then act in an unwise manner, patient autonomy must be honoured.

#### A7. To make better decisions about my treatment options

**To choose how much detail I want.** MRI scans yield a vast amount of data, captured in perhaps 200 images which take a skilled radiologist several hours to interpret and generate a report that is one of the most complex items found in medical notes<sup>67</sup>. Consequently, Epstein and colleagues<sup>68</sup> point out that providing too much information can obfuscate rather than clarify, especially when the person is under emotional and physical strain - and this may lead to the person failing to take the necessary action because they can no longer see the main issue. This underlines the importance of providing information in accessible ways, so that people retain control of their own learning, rather than having information rationed by health professionals.

**To receive treatment for previously unrecognised problems.** In the event that the scan reveals an incidental finding of clinical significance which is treatable, the person should be informed. In Shoemaker et al's<sup>69</sup> model, representatives of the local health system work with the scanning service to set the threshold for recommending when the scanned person should make an appointment with their doctor and follow up on abnormal findings, thus moderating the level of demand. Indeed, this binary decision, to seek medical attention or not is the most succinct summary of the findings from the scan and needs to be considered separately from the simple delivery of a copy of an image to the person.

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<sup>65</sup> Phillips, J. P., C. Cole, J. P. Gluck, J. M. Shoemaker, L. E. Petree, D. L. Helitzer, et al. (2015). Stakeholder opinions and ethical perspectives support complete disclosure of incidental findings in MRI research. *Ethics Behav.* 332– 350.

<sup>66</sup> Mental Capacity Act 2005.

<sup>67</sup> Weingart SN, Rind D, Tofias Z, Sands DZ (2006) Who uses the patient internet portal? The PatientSite experience. *J Am Med Inform Assoc* 13:91–95. Also Keselman A, et al (2007) Towards consumer-friendly PHRs: patients' experience with reviewing their health records. *AMIA Annu Symp Proc*:399–403.

<sup>68</sup> Epstein RM, Korones DN & Quill TE (2010) Withholding information from patients — when less is more *N Engl J Med* 362;5 pp380-1. February 4. DOI: 10.1056/NEJMp0911835.

<sup>69</sup> Shoemaker et al (2016) op cit.

A small number of respondents who were interviewed by Shoemaker's team<sup>70</sup> after they had received this advice admitted that they did not act on this recommendation because they already knew about the finding or were already seeing their doctor for another reason and so did not need to make an additional appointment. This was an American study, so a few did not follow up because they could not afford the doctor's fees. Others understood the message from the scan report to be that the condition was most likely trivial, so, while the recommendation to see a doctor was made, it was precautionary and probably an excessive response, so they chose not to follow it up. A few who were advised that there was no need to visit their doctor to discuss the scan did so anyway, but this was a much smaller group than the converse, so on balance, fewer people visited their doctor than were recommended to do so.

#### A8. To prove to myself that the health service is responding

**To see the health service taking me seriously.** Scans are optional diagnostic tools, in contrast with the short appointment that the doctor is obliged to provide, so the scan provides real evidence that the person's concerns are being taken seriously<sup>71</sup>. Holding a copy of the scan image can also demonstrate to others that the health service is investing resources in the person, as discussed further below.

**To minimise the burden I am placing on the health service.** Shoemaker and colleagues<sup>72</sup> created a system for reviewing and reporting scans to the research participants<sup>73</sup> and then evaluated its use with scans taken in connection with research into psychiatric and neurodevelopmental issues and with both patients with diagnosed illness and with healthy volunteers. They found the financial and workload cost of providing the scans to be minimal.

A few hospitals in the US charge an administration fee for providing a copy of the MRI scan image to the person<sup>74</sup>, and this is expected to recoup administrative time spent on providing the image. In the UK, charges may only be levied if the request is 'manifestly unfounded or excessive' and it must be restricted to a 'reasonable fee'<sup>75</sup>. Where the image is delivered via an online portal<sup>76</sup> or as an email attachment, costs are low and fewer hospitals charge for providing this service. However, this means

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<sup>70</sup> Shoemaker et al (2016) op cit.

<sup>71</sup> The 2019-2020 NHS tariff indicates that MRI scans cost between £108 and £564 depending on the particular type of scan that is undertaken – see <https://improvement.nhs.uk/resources/national-tariff/#h2-tariff-documents>.

<sup>72</sup> See Shoemaker et al (2016) op cit.

<sup>73</sup> They received a summary report and a recommendation on whether they should see a doctor about this report or not. It is not clear from the paper whether they were offered a copy of the image.

<sup>74</sup> Lye et al 2019 op cit found 16% of their sample of 80 hospitals charged a fee.

<sup>75</sup> Data Protection Act 2018.

<sup>76</sup> A patient portal may offer some or all of the following online functions: appointment scheduling, email access to healthcare providers and access to test results (sometimes including MRI scans) and entire patient records. There is the potential for portals to create an opportunity for patients to upload their own medical history and medication details, thus saving time for professionals who might otherwise spent time searching for this information. Portals may disadvantage digitally excluded groups. See Cook et al (2016) op cit. .The potential of using portals to get scan findings direct to the patient was recognised in 2005 or earlier – see Johnson AJ, Hawkins H, Applegate KE (2005) Web-based results distribution: New channels of communication from radiologists to patients *Journal of the American College of Radiology*, Volume 2, Issue 2, 168 – 173.

that the person is reading the narrative report and viewing the scan images on their own, rather than in the presence of a professional<sup>77</sup>.

Granting patients access to health records results in a vanishingly small number of requests for information to be corrected or removed from the file – in one study this option was taken up by only one in 500 patients<sup>78</sup>. The law permits requests for information to be denied for administrative reasons, but only where acceding to the request would involve disproportionate effort<sup>79</sup>.

#### A9. To gain a memento of this experience

**To remind myself that I survived.** The scan image provides a memento of getting through this period of life<sup>80</sup>, whether that means survival through the depression that brought the person into the Brightmind research study and the experience of being scanned. For some, involvement in health research is a way to redeem the suffering endured throughout the period of illness and transform it into a blessing for others.

**To face future scans.** Remembering the first scan clearly will help me to decide whether to accept a future MRI scan.

**To display my scan at home.** A scan of the brain is a unique and deeply personal piece of property that represents a part of my life, that is particularly associated with the notion of mind and self, so some people may wish to retain it and even display it<sup>81</sup>. The particular body part which is the target of the MRI scan with its connotations of privacy and modesty might affect the person's willingness to ask for a copy or show it to others<sup>82</sup>.

## B. In relation to research

### B1. To show an interest

**To demonstrate attentive curiosity.** Some of the people who participate in health research show considerable commitment and interest in the work of the research team, with a few going on to become repeat participants or members of advisory panels on future studies. Asking for a copy of the scan is a way to show an interest in the research.

### B2. To help the team be person-centred

**To challenge researchers to think about patient perspectives.** It is part of the role of LEAP members to challenge the research team to focus on the experience of patients who go through the treatments under scrutiny, and so they use a variety of approaches to engage with the research

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<sup>77</sup> Lee et al (2016) op cit.

<sup>78</sup> Hanauer DA, Preib R, Zheng K, Choi SW (2014) Patient-initiated electronic health record amendment requests. *J Am Med Inform Assoc.* Nov-Dec;21(6):992-1000. doi: 10.1136/amiainl-2013-002574.

<sup>79</sup> Thorogood et al (2018) op cit.

<sup>80</sup> A few hospitals in the USA run online portals through which people can access their own scan images. For an example, see <https://www.advancedradiology.com/for-patients/patient-portal>. Options for providing information to patients include CD to be collected, CD to be posted out, email attachment and cine file. CD is the commonest format, but has a number of problems including (i) it has limited storage capacity compared to the need; (ii) is difficult to encrypt or password protect; (iii) is becoming an obsolete format so a diminishing proportion of the population have access to a CD reader. – see Lye et al (2019) op cit.

<sup>81</sup> For a discussion of the anthropology of artefacts, see Miller D (2010) *Stuff* Cambridge: Polity Press.

<sup>82</sup> See [https://experts.umich.edu/details/publication/81807?and\\_facet\\_profiles\\_author=2907](https://experts.umich.edu/details/publication/81807?and_facet_profiles_author=2907).

process, proactively raising questions, submitting reflections and challenging assumptions. Where a LEAP member happens to also be a research participant<sup>83</sup>, they may ask for a copy of their MRI scan in order to engage more fully with the research team.

**To ensure the findings are not compromised.** In randomised trials, research participants must not become aware of the findings during the study period (usually called ‘blinding’) and so they give up their right to access records, including the results of the scan, until the study is over, when the right of access is then reinstated. Similarly, researchers must often be blinded to the results of the MRI scan and so must not be permitted to know about it or share the findings with the person, and any system for providing the feedback from another person, such as a radiologist, neurologist or GP must also protect this blinding. Exceptions are made, of course, to address incidental findings of clinical significance. Where the person has access to their own data either in research or clinical care, they are able to exercise their legal right to correct inaccurate data and so improve data integrity. The Health Research Authority recommend placing the dataset in the public domain as it will reduce the chance that competing interests will overwhelm patient benefit, since the research team can be held to account for their conclusions<sup>84</sup>.

**To inform future treatments.** The Brightmind study concerns a 20-session programme of transcranial mental stimulation, guided by the findings from an MRI scan undertaken before the programme of treatment begins. In some cases, a second programme of stimulation may be needed after some time has elapsed. As such, retention of the scan results enables the magnetic coil to be placed appropriately, and it is entirely reasonable for the person to retain a copy of the data so that they can offer it to assist in positioning the coil at future appointments should the team mislay the information.

### B3. To hold a copy in case the original is lost by the research team

**To be my own data controller.** Johnson et al<sup>85</sup> note that there is a real risk that scan findings get lost in the healthcare system and do not get actioned by family doctors, as records ‘fall through the cracks’. Questions might be raised about the practice of researchers in relation to the curation of data<sup>86</sup>, and so providing the person with immediate access to their scan data means that they can reduce any processing and archiving challenges that may arise.

### B4. To confirm the integrity of the research

**To satisfy myself that a scan was carried out.** Receiving a copy of the image provides reassurance that the scan was not a fake, placebo or dummy and the research team are faithfully handling the data<sup>87</sup>. While this is a particular responsibility of Public Contributors who serve as Public Co-

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<sup>83</sup> See Bates P (2020) *How Public Contributors can manage overlapping roles in health research*. Available at <http://peterbates.org.uk/wp-content/uploads/2019/11/How-to-manage-overlapping-roles.pdf>.

<sup>84</sup> National Research Ethics Advisors’ Panel (2012) *Conflicts of interest/competing interests*. Health Research Authority 13 February. Page 4. Downloaded from <https://www.hra.nhs.uk/documents/272/nreap04-guidance-national-research-ethics-advisors-panel-13-february-2012.pdf> 3 August 2020.

<sup>85</sup> Johnson et al (2010) op cit.

<sup>86</sup> Krahe MA, Toohey J, Wolski M, Scuffham PA, Reilly S (2019) Research data management in practice: Results from a cross-sectional survey of health and medical researchers from an academic institution in Australia. *Health Inf Manag*, p1-9. <https://doi.org/10.1177/1833358319831318>.

<sup>87</sup> Lunshof and colleagues highlight the fact that the research participant can verify elements of the raw data in a way that often cannot be achieved after it has been processed. See Lunshof JE, Church G & Prainsack B (2014) Raw personal data: Providing access *Science* January, pp373-4. DOI: 10.1126/science.1249382. For an egregious example of fabricating and manipulating research data, see the story of Diederik Stapel – see Levelt P, Noort E, & Drenth P (2012) *Flawed science: The fraudulent research practices of social psychologist Diederik*

Applicants for research funding or sit on the Project Steering Group or Data Management and Ethics Committee, all LEAP members bear a share of the responsibility to ensure that the research team are acting properly, and it is hoped that research participants will serve as whistle-blowers should the need arise. Providing the person with a copy of their own data may enable them to carry out these checks.

**To gain benefit but not profit from participation.** There is a fine balance to be struck in which research participants should be thanked for their help, perhaps receive a small gift in recompense for the inconvenience they have endured and be enriched by the experience, but should not profit from it. Otherwise, anyone who was worried about their health could sign up to the research in order to jump the queue for an MRI scan, distorting the study sample. Shoemaker's team<sup>88</sup> debunked this theory by finding that fewer than 5% of her sample participated because they were worried about a health condition and this could well have been the subject of the study anyway. So there is little basis for researchers or clinicians worrying that providing a copy of the MRI scan would damage the research process.

#### B5. To compare it with a future scan

**To collect a time series.** Some people want to obtain a time sequence of scans, perhaps so they can see change, or simply mark some milestones in their endurance of a longstanding illness. This is hampered by the practice of some scan services, who destroy historic records<sup>89</sup>, so the only way that the person can build their archive is to ask for a copy of each scan as it occurs.

#### B6. To secure my eligibility to participate in this study or future studies

**To prove I am in the right place.** Information from the scan may confirm that the person is an eligible participant for the current study and indicate whether they may be eligible to participate in concurrent studies. In addition, the person will be able to contribute their own data to future studies.

#### B7 To design future research

**To build on this work.** This point moves the discussion on from access to the person's own individual scan to consider how the full anonymised dataset might be placed in a publicly accessible data repository so that the person can design future research in collaboration with others<sup>90</sup>.

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*Stapel.* Available at [https://pure.mpg.de/rest/items/item\\_1569964/component/file\\_1569966/content](https://pure.mpg.de/rest/items/item_1569964/component/file_1569966/content). As at April 2020, Stapel had 58 academic papers retracted – see <https://retractionwatch.com/retraction-watch-database-user-guide/>.

<sup>88</sup> Shoemaker et al (2016) op cit.

<sup>89</sup> Stip et al 2019 op cit and Lye et al 2019 note that practice varies in relation to the time period over which scans are retained. Nelson recommends that scans should be retained for a minimum period - Nelson CA (2008) Incidental findings in magnetic resonance imaging (MRI) brain research. *J Law Med Ethics.* 36:315–9, 213. Available at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2585420/>.

<sup>90</sup> Some open access repositories invite the public to donate and upload their own data to drive future research – see <https://www.openhumans.org/>. Enabling this would require the data from MRI scans that is provided to the person to meet interoperability requirements. Wolf SM & Evans BJ (2018) Return of results and data to study participants *Science* 12 Oct, Vol. 362, Issue 6411, pp. 159-160. DOI:10.1126/science.aav0005. Also Wolf SM & Evans BJ (2018) Defending the return of results and data *Science* 14 Dec, Vol. 362, Issue 6420, pp. 1255-1256. DOI:10.1126/science.aaw1851.



## B8. To conduct secondary interrogations of the dataset

**To squeeze more findings out of the original work.** Access to the full dataset in its raw, uninterpreted but anonymised state allows independent persons to conduct their own analysis and verify the legitimacy of the findings of the original research team – a basic tenet of scientific method. In addition, they will be able to interrogate the raw data, or filtered subsections of it, to answer questions not asked by the original research team.

## C. With other audiences

### C1. To prove to others that my illness is real

**To go public.** The intense experience of depression leaves many people caught on the horns of a dilemma, having to decide whether to treat the matter as private to themselves or to share their diagnosis and journey with other people and so face and combat stigma.

**To challenge stereotypes.** People with mental health issues meet people who hold stereotypical views so often that it can be reflected in their own assumptions, as they increasingly expect to be told to ‘snap out of it’ or ‘just take a bit of exercise and these feelings will go away’. To counter these views, holding one’s own copy of an MRI scan may help to show that the illness is real. There are, of course, situations where the mental illness will be very real but the scan will be normal, but the focus here is on the person’s own viewpoint and their reason for wanting a copy of their MRI scan. Clinical and research staff will need to understand the person’s own theory of mind and beliefs about the nature of depression, the utility of the scan, the process of the research and the attitudes held by others. If their view is at odds with established science, then the focus should move on to educating the person so that they have a better understanding of what the scan can and cannot reveal.

### C4. To get taken seriously, deepen relationships and get a better response.

**To negotiate with other agencies.** A wide variety of organisations may take an interest in the person’s health status and holding their own copy of scan findings and other medical information will help to empower the person. Stip et al<sup>91</sup> note that other audiences may take action which is not wanted by the person if they discover that the MRI scan has revealed abnormalities. For example, the presence of a tiny cerebral lesion which is regarded by radiologists as of no clinical significance, may be interpreted as epileptogenic or predictive of other future problems and so trigger adverse responses such as refusal of a loan, increases in insurance premiums or even job loss. The person having a copy of their scan findings may be relevant for negotiations with the family doctor, psychiatrist or second opinion doctor; occupational health department or welfare benefits officials, insurance company or vehicle driver licensing authority.

**To share with my family and friends.** Jackson’s team<sup>92</sup> asked patients if they wanted to share their medical notes with a friend or family member and then checked if they did so during the study period. The answers were that 55% wanted the option and 22% actually did so, leading to better medication adherence and self-care<sup>93</sup>.

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<sup>91</sup> See Stip et al (2019) op cit.

<sup>92</sup> Jackson SL, Mejilla R, Darer JD, Oster NV, Ralston JD, Leveille SG, Walker J, Delbanco T, Elmore JG (2014) Patients who share transparent visit notes with others: characteristics, risks, and benefits *J Med Internet Res*. Nov 12;16(11):e247. doi: 10.2196/jmir.3363.

<sup>93</sup> Jackson et al (2014) op cit.

**To gain some control of the doctor-patient relationship.** Some family doctors worry that providing scan results will mean that they lose control of the doctor-patient relationship, as patients would be more active partners and may challenge findings<sup>94</sup>. Johnson et al<sup>95</sup> ran a focus group with referring physicians who recommended building in a time delay<sup>96</sup> before the information was released to patients. This would enable doctors to speak to the patient before they received the information, and so they could provide high-quality information to help the person subsequently view the scan findings, as well as saving time on countering erroneous ideas picked up from the Internet. This wish to retain control is in direct contradiction of the established approach that shows that where patients read their own record, ask questions and participate in clinical decision-making, health outcomes improve, as well as satisfaction<sup>97</sup>. It also denies patients their request<sup>98</sup> for immediate access to their data<sup>99</sup>.

**To deepen the relationship with my own doctor.** Sexton<sup>100</sup> points to the importance of using the scan discussion as an opportunity to build the principal relationship between the person and their family doctor, rather than engaging with a range of other professionals, such as radiographers and neurologists with whom most people would have only superficial contact. Shulman et al<sup>101</sup> note that standardised disclosure practices, counselling and follow-up for patients after the information is shared, may all be needed.

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<sup>94</sup> Denneson LM, Cromer R, Williams HB, Pisciotto M, Dobscha SK (2017) A qualitative analysis of how online access to mental health notes is changing clinician perceptions of power and the therapeutic relationship. *J Med Internet Res.* Jun 14;19(6):e208. doi: 10.2196/jmir.6915.

<sup>95</sup> Johnson et al (2010) op cit.

<sup>96</sup> Lee et al (2016) op cit note that a delay has been built into some online portals varying from a few days to two weeks between the radiologist's report being finalised and it being made available for the patient to view. A delay may provide short term benefit for patients, as shown by a study that found that patients who were given scan results after 2 days reported less wellbeing than those who were not given their results until 6 months had passed.

since the scan. See Ash LM, Modic MT, Obuchowski NA, Ross JS, Brant-Zawadzki MN & Grooff PN (2008) Effects of diagnostic information, per se, on patient outcomes in acute radiculopathy and low back pain. *Am J Neuroradiol*, 29, 1098-103.

<sup>97</sup> This was demonstrated through a randomised control trial (RCT) as long ago as 1985, but, as shown elsewhere, some stakeholders feel that scan findings are an exception to the general rule. We might wonder how many other clinical areas or professional groups consider their work to be a legitimate exception to the general principle that they endorse. For the RCT, see Greenfield S, Kaplan S, Ware JE Jr (1985) Expanding patient involvement in care: Effects on patient outcomes. *Ann Intern Med.* Apr;102(4):520-8. DOI: 10.7326/0003-4819-102-4-520

<sup>98</sup> Patients have a diverse array of wishes about whether incidental findings should be returned to them – see Clift KE, Halverson CME, Fiksdal AS, Kumbamu A, Sharp RR, McCormick JB (2015) Patients' views on incidental findings from clinical exome sequencing *Applied & Translational Genomics*, Volume 4, Pages 38-43. ISSN 2212-0661, <https://doi.org/10.1016/j.atg.2015.02.005>. Where the person sets out their preference that some information is not wanted, this generates a confidentiality challenge to ensure that other healthcare professionals involved in the person's care also understand the outcome of this discussion and avoid inadvertently breaching the agreement. See McCormick et al (2014) op cit.

<sup>99</sup> Johnson AJ, Easterling D, Williams LS, Glover S, Frankel RM (2009) Insight from patients for radiologists: improving our reporting systems. *J Am Coll Radiol.* 2009 Nov;6(11):786-94. doi: 10.1016/j.jacr.2009.07.010.

<sup>100</sup> Sexton SM (2014) How should we manage incidentalomas? *Am Fam Physician* 90(11):758–9.

<sup>101</sup> Shulman MB, Harkins K, Green RC, MD, Karlawish J (2013) Using AD biomarker research results for clinical care A survey of ADNI investigators *Neurology* 81 September 24 -1121

**To recruit other professionals to my team.** The process of obtaining an MRI scan and then discussing its findings may offer opportunities to engage with previously unfamiliar disciplines, such as radiographers and neurologists, who may be able to help the person acquire a useful diagnosis or improve their treatment,

**To get better care.** Stip et al<sup>102</sup> note that one benefit of taking part in health research is the possibility that it will lead to more assiduous medical care.

#### C5. To ask good questions

**To read the scan.** People who have never seen the output from an MRI scan will not know whether a lay person will be able to ‘read’ it or not, and so may wish to try. Some of the people scanned may have relevant training and those who do not may find that viewing the image prompts them to ask questions and learn more than they would do otherwise.

**To question the radiologist.** Research has found that patients want the opportunity to have a discussion with the radiologist<sup>103</sup>, which was a worry for those who attended Johnson et al’s<sup>104</sup> focus group. Cook et al<sup>105</sup> recommend that the contact details of the radiologist who provides a clinical interpretation of the scan are made available to the person themselves and their doctor, thus enabling follow up discussions to take place but increasing workload pressure and calling for sophisticated communication skills..

**To find answers.** While providing scan images and talking about them may indeed be time-consuming, Kole & Fiester<sup>106</sup> point out that failing to educate and support people has consequences too, and, indeed, even more health service time may be taken up in allaying anxieties and correcting misunderstandings amongst people who were not properly informed from the outset. The OpenNotes project found that using an online portal to read medical notes did not lead patients to book more appointments with their doctor<sup>107</sup>, while Lee’s team report<sup>108</sup> ‘no appreciable slowdown’ for radiology departments after patient access via an online portal has been introduced. Similarly, Henshaw’s team<sup>109</sup> found that 86% of referring physicians experienced either no change or a

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<sup>102</sup> Stip et al (2019) op cit.

<sup>103</sup> See Davis TG, Callen J Georgiou A, Westbrook JL, Greisinger A, Adol Esquivel A, Forjuoh SN, Parrish DE, Singh H (2015) Releasing test results directly to patients: A multisite survey of physician perspectives *Patient Education and Counseling* Volume 98, Issue 6, June 2015, Pages 788-796. Also Pahade J, Couto C, Davis RB, Patel P, Siewert B & Max P. Rosen MP (2012) Reviewing imaging examination results with a radiologist immediately after study completion: Patient preferences and assessment of feasibility in an academic department *American Journal of Roentgenology*. 199: 844-851. Available at: <https://www.ajronline.org/doi/10.2214/AJR.11.8064>. Also Rosenkrantz AB & Flagg ER (2015) Survey-based assessment of patients' understanding of their own imaging examinations. *J Am Coll Radiol*. Jun;12(6):549-55. doi: 10.1016/j.jacr.2015.02.006. Also Miller P, Gunderman R, Lightburn J, Miller D (2013) Enhancing patients' experiences in radiology: through patient-radiologist interaction. *Acad Radiol*. Jun;20(6):778-81. doi: 10.1016/j.acra.2012.12.015.

<sup>104</sup> Johnson et al (2010) op cit.

<sup>105</sup> Cook et al (2016) op cit.

<sup>106</sup> Kole and Fiester (2013) op cit..

<sup>107</sup> Leveille SG, Mejilla R, Ngo L, Fossa A, Elmore JG, Darer J, Ralston JD, Delbanco T, Walker J (2016) Do patients who access clinical information on patient internet portals have more Primary Care visits? *Med Care*. Jan;54(1):17-23. <https://www.ncbi.nlm.nih.gov/pubmed/26565525>.

<sup>108</sup> Lee et al 2016, op cit.

<sup>109</sup> Henshaw et al (2015) op cit.

decreased amount of traffic via emails, phone calls and appointments booked by patients who were given access to their imaging results via an online portal.

## C6. To build peer networks

**To link up with peers.** If the person is provided with clear information about their particular health status, this may assist them in building social networks with others who share the same condition.

## C7. To Complain

**To get wrongs put right.** Where things go wrong, the person should have recourse to a complaints system and access to formal liability mechanisms<sup>110</sup>. Some complaints may arise because of the difference in timing, as researchers may not spot the incidental finding until months or years have passed since the scan was undertaken<sup>111</sup>, and so providing evidence to the person would potentially spotlight this delay, which, while it may be unimportant to the research process, could be fatal to the person.

**To improve service delivery.** Reports that are written down and provided to patients, rather than communicated in less formal ways, invite challenge. The focus groups convened by Johnson et al<sup>112</sup> hinted that, as feedback is increasingly recorded, transparent and accessible to patients, so there is a corresponding increase in risk-averse behaviour and the use of qualifiers and vague statements, resulting in the reports becoming less and less useful. These fears are not upheld in practice, though, since in a broader context, patient access improves the quality of reporting; brings earlier attention to problems and prevents inappropriate actions being taken that could harm the person or others; and aids informal resolution rather than medico-legal responses<sup>113</sup>.

## Conclusion

Drawing together the many creative ideas from the Brightmind LEAP has generated many potential reasons that may drive a person to ask for a copy of their MRI scan. Whilst some of these ideas have appeared in the literature for the past two decades<sup>114</sup>, many are only briefly explored, and some are

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<sup>110</sup> Cross NM, Hoff MN, & Kanal KM (2018) Avoiding MRI-Related Accidents: A Practical Approach to Implementing MR Safety *Journal of the American College of Radiology* Volume 15, Issue 12. Pages 1738-1744. Available at <https://doi.org/10.1016/j.jacr.2018.06.022>.

<sup>111</sup> The longest delays occur when researchers reanalyse archived data collected for a previous study. This situation is further complicated when the data is partly anonymised so that the second researcher cannot re-identify the person but the original researcher retains a key to enable them to do so. Stip et al 2019 op cit.

<sup>112</sup> Johnson et al (2010) op cit.

<sup>113</sup> Lee BS, Walker J, Delbanco T, et al (2016). Transparent electronic health records and lagging laws. *Ann Intern Med*. 165:219–220. DOI: <https://doi.org/10.7326/M15-2827>.

<sup>114</sup> For older discussions, see Deslauriers, C., E. Bell, N. Palmour, B. Pike, J. Doyon, and E. Racine. 2010. Perspectives of Canadian researchers on ethics review of neuroimaging research. *Journal of Empirical Research on Human Research Ethics* 5:49–66. Available at <https://www.ncbi.nlm.nih.gov/pubmed/20235863>. Also Mason MK (2014) Looking for trouble—patient preference misdiagnosis and overtesting: a teachable moment. *JAMA Intern. Med.* 174:1548–1549. Available at [https://www1.ucdenver.edu/docs/librariesprovider81/resident-vignettes/lookingfortrouble-patientpreference-misdiagnosisandovertesting-ateachablemoment.pdf?sfvrsn=46ef44b9\\_2](https://www1.ucdenver.edu/docs/librariesprovider81/resident-vignettes/lookingfortrouble-patientpreference-misdiagnosisandovertesting-ateachablemoment.pdf?sfvrsn=46ef44b9_2). Also Milstein AC (2008) Research malpractice and the issue of incidental findings. *J. Law Med. Ethics* 36:356–360. Available at <https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1748-720X.2008.00280.x>. Also Orme, N. M., J. G. Fletcher,

missing entirely. More significantly, almost all the material is written to support the work of health professionals and researchers rather than uphold the rights of the individual. A research project that investigates the motivations of research participants in this field will break new ground.

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H. A. Siddiki, W. S. Harmsen, M. M. O’Byrne, J. D. Port, et al. 2010. Incidental findings in imaging research evaluating incidence, benefit, and burden. *Arch. Intern. Med.* 170:1525–1532. Available at <https://www.ncbi.nlm.nih.gov/pubmed/20876402>. Also Royal JM & Peterson BS (2008) The risks and benefits of searching for incidental findings in MRI research scans. *J. Law Med. Ethics* 36:305–314. Available at <http://europepmc.org/backend/ptpmcrender.fcgi?accid=PMC4290840&blobtype=pdf>. Also Schmidt CO, Hegenscheidt K, Erdmann P, Kohlmann T, Langanke M, Volzke H, et al. (2013) Psychosocial consequences and severity of disclosed incidental findings from whole-body MRI in a general population study. *Eur. Radiol.* 23:1343–1351. Also Shaw RL, Senior C, Peel E, Cooke R, & Donnelly LS (2008) Ethical issues in neuroimaging health research: an IPA study with research participants. *J. Health Psychol.* 13:1051– 1059. Available at [http://publications.aston.ac.uk/id/eprint/16617/1/Shaw\\_et\\_al\\_JHP\\_2008\\_13\\_1051-1059.pdf](http://publications.aston.ac.uk/id/eprint/16617/1/Shaw_et_al_JHP_2008_13_1051-1059.pdf). Also Wardlaw JM & Jackson A (2013) Workup and Management of incidental findings on imaging. *Evid. Based Neuroimaging Diagn. Treat.* 10.1007/978-1-4614-3320-0\_4. Abstract at [https://link.springer.com/referenceworkentry/10.1007%2F978-1-4614-3320-0\\_4](https://link.springer.com/referenceworkentry/10.1007%2F978-1-4614-3320-0_4).