

Navigating the grey areas: The ethics of incidental findings in Radiology

Introduction

Modern medicine is built upon 4 pillars of ethics that are engrained into our minds from the beginning of medical school: autonomy, beneficence, non-maleficence and justice. These 4 notions should underpin every aspect of clinical practice across all fields of medicine.

Incidental findings are defined by the Royal College of Radiologists (RCR) within research as 'a finding that has potential health or reproductive importance, unknown to the participant, which is discovered unexpectedly in the course of conducting research, but is unrelated to the purpose and beyond the aims of the study'.¹ The American College of Radiology also define incidental findings as 'an incidentally discovered mass or lesion detected by CT, MRI, or other imaging modality performed for an unrelated reason'.²

With the use of medical imaging ever increasing per patient, and the quality of images and technology available improving, one can assume the frequency of incidental findings will rise. Thus, radiologists today need to be aware on how to approach these findings in ethically appropriate ways, keeping the 4 pillars above in mind; yet guidance on this topic in the UK still remains unclear.³

Background

Studies have shown the mean frequency of incidental findings in research to be 23.6%, with this rising to 31.3% in CT imaging.⁴ So, radiologists will most likely come across incidental findings at some point in their career and must consider both the burden and benefit that disclosure will provide, and which outweighs the other. As Graham et al (2021) discuss, whether incidental findings should be disclosed in concordance with a patient's best interests can be summarised in three concepts; clinical utility, validity, and actionability.⁵

Clinical utility refers to the possible health or reproductive importance an incidental finding will have to the patient, present or future. Validity refers to the accuracy and reliability of the finding and scan itself. Actionability refers to the possible treatment or management of the pathology revealed by the incidental finding. Most agree incidental findings which are valid, actionable and of clinical significance to patients are seen as reasonable to be disclosed.⁵

Law

The standard of acceptable medical practice in law has shifted from what the majority of medical professionals deem okay (the Bolam test⁶ in England), towards what the majority of patients themselves would want to know, following the Montgomery ruling.⁷ Whilst the ruling was primarily concerned with consent, it reiterates that clinicians should treat patients in accordance with their best interests, including providing all information the patient themselves would find relevant.⁸ Applying this to incidental findings, it would suggest that the patient should be fully informed if they express that they would want to be, as only they know what is right for them and how that information would influence their lives.

Autonomy

Some argue that disclosing incidental findings provides a net benefit to patients and demonstrates respect for their autonomy.⁵ However, the patient themselves is the best judge of whether knowing this information is likely to benefit or harm them, as they will have better insight into their non-clinical interests than the doctor. Many may feel that complete knowledge and understanding of oneself is integral to their autonomy, and thus incidental findings may influence future decisions. For example, if an intact aneurysm is found and disclosed, the patient may make the decision to give up contact sports or have surgery.⁵ The importance in that example is that the patient is given the opportunity to be informed and make their own decision based upon information disclosed.

On the other hand, autonomy as a principle can be used as an argument against disclosure of incidental findings. Whilst patients can be seen as having the right to be informed to uphold autonomy, it can also be argued that they have the right not to be informed. This is often argued in the case of genetic screening⁹, but this concept can also be applied to the context of incidental findings. Respect for one's autonomy with regards to incidental findings is complex as they are unexpected by nature, and it is often too late to clarify what a patient wants and does not want to know.¹⁰

Whilst patients may retrospectively approve of clinicians' decisions, it can be argued that their autonomy is inherently undermined in some form, by losing some aspect of control over the decision-making process.¹¹ A clinician will have feelings of responsibility and duty of care towards their patient, and may feel that it is inappropriate to observe incidental findings but not report; however, the argument for whether this outweighs patient autonomy is not clear-cut.

Duty of candour

In the UK clinicians have a statutory duty of candour, which applies to medical errors, but could be extrapolated to encourage full disclosure of incidental findings.

However, in practice it is rarely the radiologist that communicates the findings of a scan, and instead that role falls to the referrer. Standardly, radiologists carry out practice 'at a distance from the patient'¹², so whilst the referrer may have better standing to judge the implications of the finding, the radiologist would still need to attach some form of evaluation to the report. This can complicate the situation in the event of harm due to an incidental finding, and support disclosure.

Non-maleficence

An issue with incidental findings and their disclosure is that they may be of uncertain clinical significance. These findings may then go on to subject patients to unnecessary tests, diagnoses or interventions, opposing the ethical pillar of non-maleficence. Furthermore, incidental findings could bring about anxiety and psychological harm or burden. As Saeleart et al (2020) argue, patient agreement with disclosure may just be a psychological coping mechanism to help come to terms with information that the patient cannot unlearn.¹¹ Mandatory reporting of incidental findings also assumes that the preference to be informed is the rational preferences because it is well-informed, and could be viewed as an exercise of 'soft paternalism'¹³, a practice which modern medicine has tried to move away from.

Classification of incidental findings

In terms of reporting, incidental findings would need to be classified; some as serious, others less so, some perhaps completely benign. Thus, when discussing mandatory disclosure, where should the line be drawn on which classifications should be reported? What may be physiologically benign may still have significance to an autonomous patient and their views of themselves, as previously discussed. Who decides, based on what criteria? This highlights the imperative need for explicit and unambiguous guidance on the topic.

Resources

Pursuit of incidental findings could be viewed as an unjust allocation of limited resources, unless equal access to the kinds of results and follow-ups they require could be guaranteed for all patients. As the RCR states, there is a shortage of radiologists in the UK.¹ Therefore, it is not logistically feasible for equal attention to be applied to all incidental findings, including benign ones, on top of all other imaging conducted on a day to day basis for diagnostic purposes.

Opt-out system

Other organisations dealing with similar matters have suggested possible opt-out systems for patients, such as the American College of Medical Genetics and Genomics, with regards to secondary findings in genetic testing.¹⁴ Perhaps then, a similar system could be applied to radiology. However, there are many challenges with this plan. To begin with, patients may not know what they are truly opting out from; patients will have varying health literacy, and the scope of incidental findings is vast. Moreover, the notion of 'opting out' may offer short term comfort to the patient but will not change any potential medical risks as a result of the incidental finding(s) in the future. However, the system would help patients and professionals reach decisions collaboratively, ensuring both parties' views are upheld.

Conclusion

Incidental findings raise a number of ethical challenges for professionals. Both disclosure and 'opt-out' systems help maintain the integrity of patient autonomy, and reporting findings can be seen as acts of both beneficence and non-maleficence. At their core, medical discussions in practice are heavily nuanced, should involve cooperative exchanges of information, and maintain a delicate balance between the pillars of medical ethics. Justifications and objections towards reporting incidental findings are socially, individually, economically and scientifically context-dependent and we may see a shift in attitudes in the future regarding the debate. What is needed at present is clear guidance on reporting incidental findings, removing a degree of subjectiveness in practice, with the ultimate goal of benefiting both patients and clinicians.

References

- 1) The Royal College of Radiologists. (2011). *Management of Incidental Findings Detected During Research Imaging*. London: The Royal College of Radiologists.
- 2) American College of Radiology. (2016). *Incidental Findings*. [Online]. Available from: <https://www.acr.org/Clinical-Resources/Incidental-Findings#:~:text=An%20incidental%20finding%2C%20also%20known,perfor med%20for%20an%20unrelated%20reason.%E2%80%9D>. [Accessed 10 Oct. 2023].
- 3) Booth, T.C., Jackson, A., Wardlaw, J.M., Taylor, S.A. and Waldman, A.D. (2010). Incidental findings found in 'healthy' volunteers during imaging performed for research: current legal and ethical implications. *British Journal of Radiology*. **83**(990), pp.456–465.
- 4) Lumbreras, B., Clark, L.E. and Idefonso Hernández-Aguado (2010). Incidental findings in imaging diagnostic tests: a systematic review. *British Journal of Radiology*. **83**(988), pp.276–289.
- 5) Graham, M., Hallowell, N. and Savulescu, J. (2021). A Just Standard: The Ethical Management of Incidental Findings in Brain Imaging Research. *Journal of Law Medicine & Ethics*. **49**(2), pp.269–281.
- 6) *Bolam v Friern Hospital Management Committee* [1957] 1 WLR 582.
- 7) *Montgomery v Lanarkshire Health Board* [2015] SC 11 [2015] 1 AC 1430.
- 8) Chan, S., Tulloch, E., Cooper, E., Smith, A., Wojcik, W. and Norman, J.E. (2017). Montgomery and informed consent: where are we now? *BMJ*, [online]. **357**. pp.j2224–j2224. Available from: <https://www.bmj.com/content/357/bmj.j2224> [Accessed 12 Oct. 2023].
- 9) Berkman, B.E. and Hull, S.C. (2014). The 'Right Not to Know' in the Genomic Era: Time to Break From Tradition?. *American Journal of Bioethics*. **14**(3), pp.28–31.
- 10) Christenhusz, G.M., Devriendt, K. and Dierickx, K. (2012). To tell or not to tell? A systematic review of ethical reflections on incidental findings arising in genetics contexts. *European Journal of Human Genetics*. **21**(3), pp.248–255.
- 11) Saelaert, M., Mertes, H., Moerenhout, T., De Baere, E. and Devisch, I. Ethical values supporting the disclosure of incidental and secondary findings in clinical genomic testing: a qualitative study. *BMC Med Ethics*. **21**, 9.
- 12) The Royal College of Radiologists. (2022). *Professional Duty of Candour: Guidance for Radiologists*. London: The Royal College of Radiologists.

- 13) Fateh-Moghadam, B. and Gutmann, T. (2013). Governing [through] Autonomy. The Moral and Legal Limits of 'Soft Paternalism'. *Ethical Theory and Moral Practice*. **17**(3), pp.383–397.
- 14) American College of Medical Genetics and Genomics. ACMG policy statement: updated recommendations regarding analysis and reporting of secondary findings in clinical genome-scale sequencing. (2015). *Genetics in Medicine*. **17**(1), pp.68–69.