Research projects and disclosure of information.

One issue that arises fairly frequently in research is whether information that is revealed during the course of the study should be disclosed, either to participants or third parties. The decision as to whether to disclose can arise in a variety of situations, for example:

- incidental findings of medical investigations (e.g. abnormalities found in MRI scans or eye-tests)
- participants expressing the intent to harm themselves or others
- when illegal activities by participants come to light
- if unethical practice is revealed by staff working at organisations where the research is being carried out.

The issue of whether to disclose needs to be considered on a case-by-case basis for each research project.

Although it may seem that participants should always be informed about abnormalities found in medical tests, this needs to be balanced against their autonomy (right not to be given findings if they do not wish to be). Implications for family members or partners e.g. in the case of genetic conditions or sexually transmitted infections, also need to be taken into account. Another consideration is whether the researcher is qualified to interpret the results and the further support that is available for the participant (e.g. his/her GP, counselling). It should be made clear that the findings indicate a problem that requires further investigation, rather than being a formal diagnosis. A further consideration is if the researcher is passing on information about a potentially serious medical condition. Does the researcher have the expertise to do this and how much support should he/she be providing to the participant before referral to another party? How quickly will this further support be available if the findings are highly distressing for the participant? There may be an impact on the participant’s insurance or future employability as a result of the findings and these must also be considered at the planning stages of the research.

Also of importance is the measure that has been used to obtain the information. If the results of a questionnaire have suggested suicidal intent, for example, how robust is this measure clinically? The researcher can be seen to have a duty of care to pass this information on to a third party (e.g. the person’s G.P.), but the point at which this should occur may not always be clear. As well as providing details in the information sheet, researchers should discuss their intent to pass the information on to third parties with participants when the situation arises, providing this is feasible and the safety of the researcher will not be compromised.

The issue of disclosure becomes even more complex in the area of illegal activities. When a researcher is working with certain groups of participants, for example people who take illegal drugs, this issue will arise. Clearly, a great deal of valuable research takes place within these areas and the issues
must be carefully addressed. In general, there is no legal obligation to report an offence (except in certain terrorism and money laundering cases), but careful consideration of the Serious Crime Act 2007 should be undertaken by the researcher. This Act deals with offences such as assisting or encouraging an offender, which may impose a duty to act in order to avoid liability. Legal advice may need to be sought.

In the instance of an employee revealing unethical or bad practice, this should generally be disclosed, but there are also a number of factors that need to be considered. Is the researcher also employed at the organisation? Is the bad practice likely to be dangerous, for example, if the research is taking place in a medical setting, or illegal (e.g. fraud)? Who should the information be disclosed to? Are there any negative consequences that may arise for the researcher if he/she does this, for example if he/she works at the organisation?

Our Research Ethics Subcommittee or Faculty Research Ethics Panel (depending on where the application was made) will want to be certain that the researcher has weighed up the various factors prior to making their application and that the approach is justified. This will serve to reduce the risk to the researcher, as problems are less likely to occur later on. Researchers also need to ensure that they are complying with any professional codes of practice and any policies within the organisation in which they are working. When working with a group of participants where disclosure is likely to occur, there should be a clause on the information sheet stating that if certain details are revealed, they will need to be passed onto third parties. If research involves medical tests, the researcher should consider carefully beforehand whether results should be fed back to participants, their rights in saying they do not want this information and in the case of genetic or infectious conditions, whether others also need to be made aware and who should inform them. Any impact on insurance and employability must be made clear to participants beforehand. Students must always notify their supervisors should issues of disclosure arise and all researchers must notify the appropriate ethics committee, unless this has been addressed in sufficient detail in the ethics application. Even when all factors have been addressed in detail beforehand, situations may arise when it is not clear whether disclosure should take place. These should be discussed by the research team and referred to the Research Ethics Subcommittee or Faculty Research Ethics Panel immediately.

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