Healthcare Data: Is Consent the Answer?

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Consent and Healthcare

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Consent is a key concept in the provision of health care:

• **Ethical perspective**, consent forms an essential component of the moral right of individuals to autonomy over their own bodies & info. and is based on the principle of free agency.

• **Legal perspective**, consent is defined in terms of an agreement or process by which the rights of individuals to agree or to refuse treatment are upheld.

• **Practical terms**, consent refers to the process by which a health care provider informs a consumer of their treatment options, and associated risks and benefits, and supports them to make a decision about their care and information sharing to support it.
• Direct care purposes are those of a clinician or care worker with a legitimate relationship to treat a patient. The sharing of personal confidential data for these purposes has a direct benefit for the individual.

• Information sharing for the purposes of direct care and kept within the boundaries of the NHS are generally accepted.

• However we have begun to face questions about the legality of the doctrine of implied consent even for direct care.
• Sharing personal confidential data for Indirect care purposes are those that are not for the primary treatment or care of an individual. They include the analysis of information for research, commissioning or payment of service providers and audit of services.

• Indirect care does require explicit consent for sharing of information

• There are still exceptions!
Informed consent

What exactly is *informed* consent?

To be fully informed, it is necessary to:

- have been given all relevant information about the options: purpose of use, consequences of exercising the option or of not exercising that option; further or subsequent options that may be possible; whether one can change one’s mind and, if so, what the consequences will be (it may not be possible to undo the sharing of information after permission is given).
• There are too many laws, regulations and professional obligations in the area of objection to medical information sharing now.
• There is no evidence which suggests that this complex framework is consistently applied across the hugely fragmented NHS.
• The framework was developed for a paper world and does not apply so well to the new digital environment which health is being catapulted into.
• ‘…..patients are now widely regarded as persons holding rights, rather than as the passive recipients of the care of the medical profession. They are also widely treated as consumers exercising choices… The idea that patients were medically uninformed and incapable of understanding medical matters was always a questionable generalisation.’ Montgomery v Lanarkshire Health Board (2015) UKSC 11
Conclusions: Streamlined Framework?

• Patients are more aware than ever that they have the right to object to the sharing of some of their data but are still blissfully unaware of the data sharing that currently happens without their consent and that which doesn’t happen which might lead to their harm.

• Patients are unaware of the benefits to society of sharing information, which could help to improve treatments or services.