

GMC Response to the Consultation on the Draft Code of Practice on Protecting the Confidentiality of the Service User

Set out below are our comments on your draft Code of Practice on Protecting the Confidentiality of Service User Information. As suggested, I have answered your specific questions before commenting on the draft in much greater detail.

I should state that, notwithstanding the large number of detailed comments, I found the draft Code an interesting and helpful analysis of all the relevant issues. This is an extremely difficult subject to address, particularly considering the lack of a PIAG (Patient Information Advisory Group) style body to approve *strong* public interest disclosures.

As you probably know, the General Medical Council licenses doctors to practise medicine in the UK under the provisions of the Medical Act 1983 (as amended). Our objective, as defined in the Act, is to "protect, promote and maintain the health and safety of the public". Our four main functions are:

- a. to keep up-to-date registers of qualified doctors;
- b. to foster good medical practice;
- c. to promote high standards of medical education;
- d. to deal firmly and fairly with doctors whose fitness to practise is in doubt.

Within the terms of Section 35 of the Medical Act, we have power to advise doctors on standards of professional conduct and medical ethics. We do this primarily through published guidance, which sets out standards that society and the profession expect doctors to follow throughout their working lives. In commenting on your draft guidance, we wish to ensure that any obligations it might impose on doctors will not be inconsistent with the standards we set for their professional practice.

Questions

1. Is the Code about the correct length (too long/too short)? If not, what should be included/left out?

I would suggest that the draft guidance is too long, although how much too long rather depends on its intended purpose. If it is intended to be of use to most health and social care workers, and if they are expected to read it through or make everyday reference to it, it is much too long and detailed. If it is intended as a reference for occasional reference by Caldicott Guardians or as exceptional need arises, it could still be considerably shorter, mainly by avoiding repetition, notwithstanding the unavoidable need for repetition in reference documents.

There is considerable repetition throughout the Code, but particularly between Chapter 2 and Chapters 3, 4 and 5. Chapter 2 addresses much more than its stated purpose and provides a (fairly detailed) summary of much that follows. It also pre-empted some of that discussion; paragraph 2.19 states that service users should be informed of the categories of people and organisations to which (presumably identifiable) information may need to be passed for health and social care services to function (by which I assume financial and management functions are meant or included), when the lawfulness of such disclosure is debatable and addressed more thoroughly in Chapter 3.

Appendixes 3, 4, 5, 6, 10 and 11 could be deleted. The meat of any guidance they contain is (or could be) included in the text, while *Further Information and Guidance* could point to sources of information on relevant issues for the particularly interested reader to follow up.

2. Does the Code address the right range of issues? If not, what else would you like to see explicitly addressed?

The Code addresses the right issues. It also explores in considerable detail the legal (and to a lesser extent, the ethical) basis for confidentiality in healthcare, when and why disclosures are permissible, etc.

Such detail might be of interest or use to those with a particular interest in or responsibility for information governance, but may only serve to deter others from making use of what (at its core) is a potentially very useful piece of guidance for health and social care professionals in Northern Ireland.

3. Are there any paragraphs which you thought needed greater explanation or clarification? (Give numbers and what else you would like included.)

On the contrary: many or most of the paragraphs need less explanation, which all-too-often obfuscates the main point, which is or could be clearly made.

An exception to this might be a need for a preamble to Chapter 2 outlining some key terms and the focus of the guidance. It might be clearly stated, for example, that anonymised and aggregated information falls outside the scope of much of the detailed guidance that follows.

4. Is the distinction between the 3 main purposes for considering uses or disclosures clear and useful? If not, what different approach would be clearer or more useful?

The distinction between the primary use (for the care of service users) and secondary purposes is clear. The further distinction between secondary uses of overriding public interest and those of *strong* public interest is less clear. Of course we recognise the difficulty in drafting guidance in the absence of a PIAG-style function for approving the latter and the draft represents a good attempt.

5. Is it clear when implied consent is sufficient and express consent necessary for the use and disclosure of service user information? If not, how could this be clarified?

This is reasonably clear, although there is some confusion or vagueness in Chapter 3 with regards to the need to (i) provide information and (ii) ascertain the service user's appreciation of that information in order to infer consent.

In particular, paragraphs 3.5 and 3.6 are contradictory: the former states that 'the consent of the service user to the disclosure of information necessary for their care may be inferred from their acceptance of that care', whereas the latter states 'the compliance of a service user alone is not sufficient basis to infer their consent to the use of disclosure of their information'. Unless the distinction rests on their acceptance of care (which would be splitting hairs), this is contradictory and confusing.

Paragraphs 2.13-2.22 rehearse in various terms the obligation to provide information to patients, but as a fair processing obligation and as a precursor to inferring consent to its use and disclosure. In fact, 2.18 provides a more helpful summary of the obligation than the preceding paragraphs combined.

It is clear that staff are under an obligation to inform service users about the information held and to which purposes it might be put, what protections there are and what choices they have. Obligations to ensure service users are aware of that information or even that they understand it are far more onerous and difficult to measure.

Paragraph 2.15 requires that service users be made aware of the people with whom information may need to be shared to support their care, while 2.19 highlights the categories of people and organisations to which information may need to be passed for health and social services to function. While a valid distinction might be made between the identification of individuals with whom a service user might have contact and those organisations and anonymous individuals to whom information might be disclosed for secondary purposes, this is not made clear in the guidance.

See further detailed comments on the draft about this.

6. Is the ethical and legal basis for secondary uses clear? If not, how could this be clarified?

The ethical basis (or argument in favour) of secondary uses (which are not statutorily required or meet the classic *overriding* public interest test) is clearly made. The legal basis is less so, given that PIAG's role does not extend to Northern Ireland.

7. Is the ethical and legal basis for making disclosures in the public interest clear? If not, how could this be clarified?

By creation of a PIAG-style body to consider and authorise uses that would then be lawful. Failing that, the guidance makes a valiant attempt at squaring a circle. It does represent something of a shift from the classically tightly defined public interest disclosure justification and, as such, might jar with readers' understanding of the law and existing guidance, including our own (see paragraph 16 of our confidentiality guidance, in particular. I should also make reference to FAQs 5 and 6 in our Confidentiality FAQs, which states that the GMC will regard implied consent as sufficient for disclosures to national and regional NHS disease registers in the public interest).

In particular, for example, paragraph 5.15 makes reference to a legal *justification* for secondary uses which are not obligatory (and presumably do not meet the classic overriding public interest test). What laws are satisfied? Certainly the Data Protection Act is unlikely to be problematic, but whether such disclosures satisfy the Human Rights Act or the common law must remain debatable. One might expect disclosures in Northern Ireland identical to or very similar to those approved by PIAG in England and Wales to be acceptable to the courts, although they necessarily lack the objective assessment provided by PIAG.

Serious consideration should be given to the necessity of disclosures in the *strong* (but not *overriding*) public interest if they are of a different nature than those approved by PIAG in England and Wales. What special considerations apply in Northern Ireland that would justify such disclosures? Some warning about the particular challenges facing such disclosures might helpfully be included in the Code.

8. Are the "Examples of Confidentiality Decisions in Practice" useful? If not, can you suggest any other examples?

The examples are fine, but the discussions that follow are confusing, incorrect or both:

- The discussion following scenario 1 provides no solution. It should suggest an assessment of the service user's capacity; if it is lacking, a best interests test should be advocated, involving discussions with those close to and already in contact with the service user and health/social care staff to ascertain his wishes/interests;
- The discussion following scenario 2 is very confusing. It states that 'It looks likely that she has the capacity to withhold such consent and can do so even against her best interests'. While she can indeed withhold her consent, that is

not binding on staff – she is not 18 – who should disclose (without consent if necessary) if a young person (under 18) is at risk of serious harm (e.g. sexual abuse) if that’s in her best interests. Indeed, doctors would be obliged to justify a decision not to disclose in such circumstances (see *0-18 years: guidance for all doctors*). Reference to the Gillick test seems out of context here, but in any event best interests form a key part to the five tests laid down in that case. If the public interest referred to in that discussion is a reference to the girl’s young siblings, that should be spelled out (notwithstanding the basic error in suggesting competent children can opt to continue to risk serious harm by refusing consent to disclosure). Finally, ‘namely’ in the second line of the discussion might be replaced with ‘rather, it is related to’ and to the public interest mentioned at the very end of page 29 might be added mention of the girl’s own confidentiality interest.

- It would be helpful to spell out in the discussion after scenario 3 that consent in such circumstances can be inferred in the absence of objection.
- The discussion after scenario 4 states ‘[1]users must be informed about such potential disclosures and of their right to object. [2]The express consent of service users is necessary to justify such disclosures’. What is the advice? That such disclosures can be made on an implied consent basis, as suggested by 1? Or that express consent is needed as stated at 2?

If reference is to be made to children’s records, a scenario dealing with parental access (e.g. when such access is opposed by a parent with custody following divorce) might be helpful. It is a topic we are regularly asked about (see paragraphs 54 and 55 of *0-18 years: guidance for all doctors*).

Other scenarios that appear to cause difficulty relate to dual responsibilities of occupational health professionals, insurance applications and claims and similar concerns about pensions and state benefits. All lend themselves to interesting and illuminating scenarios.

General comments

The guidance is fairly negative in tone. It rightly promotes the protection of confidential information, but (perhaps because it lacks any preamble about anonymising/pseudonymising/aggregating data for legitimate uses or a positive declaration about sharing information with patients’ consent for their and common benefit) it might be perceived as a block on legitimate uses.

There is considerable repetition within and between chapters. Some fairly straightforward issues are debated in lengthy fashion, when a shorter, summary approach would be more accessible.

Children are mentioned occasionally in the draft Code, but not always where their position is different, or sufficiently to tease out their special status while upholding their privacy rights, or indeed correctly in all cases (see comments regarding scenario 3, above, and detailed comments below). The Code might be better if children were specifically excluded from its scope.

A glossary of terms might be a helpful addition to the Code; it might avoid some of the need for repetition. Key terms requiring definition include 'express consent' and 'identifiable information/data'.

Detailed comments on text

2.2 Should the reference to '*legal* consequences' be to *disciplinary* ones?

2.5 '...further used' (final sentence) than what? purposes of their care?

2.7 What are the negative effects for health and social care practice?

2.8 This paragraph is extremely long and presents the dilemma as a mathematical conundrum. There are many harms which are very likely for which disclosure would be inappropriate. They need to meet a minimum threshold of 'magnitude' before disclosure is justified, death or serious harm being the classic formulation.

2.10 The nature of protection differs, but I'm not sure that the 'level' does. What does this really mean? Is the intention to point out that disclosures might not offend the Data Protection Act while falling foul of the common law, for example? The common law of confidentiality has increasingly had to take account of human rights law and so I am not sure that they represent legal protections of a different nature or level.

2.12 This represents an early difficulty in the guidance vis-à-vis its application to children. I could not think of anyone other than a person with parental responsibility (but not necessarily a parent or guardian) who is provided for by law to take medical decisions on behalf of someone else. And even parents' powers are limited, particularly in relation to children who have capacity to consent to treatments. The Mental Capacity Act has no effect in Northern Ireland, so far as I know. This anomaly is reflected in flowchart A on page 26.

I would suggest changing the third and fourth sentences to 'This would include a person with parental responsibility for a minor who is unable to make the relevant decision for themselves. It may be appropriate to consult those close to the patient in considering what is in the best interests of other service users who lack capacity'. In the following sentence, what legal limits are there on carers and advocates (or parents) to legally represent the interests of service users, as opposed to their powers to make decisions for service users?

2.13 'possible uses' represents an onerous duty. Might 'likely' or 'proposed' uses be better? Service users should be in a position to enjoy the protection of professional and ethical obligations, as well as relevant laws. I wonder whether readers will know what the Data Protection Act fair processing requirements are (I note the appendix explaining this) and whether it adds anything of substance to the first part of the paragraph.

2.14 (last line) You might consider changing ‘protect important public interests’ to ‘disclose information in the public interest’.

2.15 This includes a reminder that service users need to be aware of their choices. In a code of practice for health and social care staff, might it not be better to include a reminder of the obligation to provide service users with information (and possibly to check service users’ understanding of that information).

2.16 Consider changing ‘the information necessary’ to ‘sufficient information’.

2.17 This paragraph is confusingly drafted and might be split up into separate points.

2.21 I wonder if the example is helpful or illuminating. Disclosure for purposes of crime detection and prosecution might be better. The question of information provision for mentally incapacitated (but not necessarily unconscious patients) is mentioned again below.

2.22 Is any of this necessary? It seems like a rather unsatisfactory introduction to the following three chapters. And is the distinction in the second bullet point (*Information*) between sensitive and other personal data, between identifiable and anonymised data, a reference to particular protections in law for specific sexual health data, or something else? There is a suggestion that some personal data can be treated less confidentially, but it’s not clear which or why.

3.1 The second sentence, in particular, is convoluted.

3.2 The final sentence might be qualified by adding ‘solely’ between ‘information’ and ‘in the ‘best interests’’. So a disclosure regarding domestic violence might be justified to protect children, if not the victim who refuses consent to disclosure.

3.5-6 These two paragraphs are confusing and apparently contradictory. The first two paragraphs of 3.5 repeat what’s gone before. The first sentence of 3.6 suggests implied consent is not an acceptable basis for such disclosures, when the final two sentences of 3.5 state that it is. This could all be much more clearly stated and in considerably shorter form.

3.7 There appear to be a couple of typographical errors in the final sentence and a qualification regarding the service user’s understanding of the information might be added to the first (notwithstanding earlier comments about the onerousness of just such advice in a code of practice)!

3.8 I am not sure that the ‘temporarily’ qualification would aid readers’ understanding, is helpful or accurate. Similarly, emergencies might warrant curtailed information provision, but they do not remove service users’ rights to refuse disclosure, which is suggested. As emergencies are covered at 3.14, I am not sure their inclusion here is necessary or helpful.

3.9 Legal obligations might be added to the first public interest in the final sentence, while the service user’s interests should be added to the second.

3.10 This paragraph is confusing and adds little or nothing to 3.9.

3.11 Is the purpose of this paragraph to suggest that disclosures should be made only where necessary? If so, that should be clearly stated. I was not sure what disclosure was referenced in the final sentence.

3.12 This is confusingly worded, repeats the end of 3.9 and probably states the obvious.

3.14 An example might illuminate this paragraph along with clarification as to whether it applies to disclosures for purposes of direct care.

3.15 There is behaviour that provides just such a basis: saying yes or signing a consent form. This paragraph should be deleted.

3.16 Court-ordered disclosures occupy an analogous position to statutorily obliged disclosures.

3.17 I am not sure what this adds and suggest its deletion.

3.18 While its part of a preamble, rather than specific advice, the 'readily' qualification in the first sentence suggests a low threshold for what follows. 'Practicably' might be a better alternative. And the purpose of the paragraph is not clear: it constitutes a statement of fact, not advice.

3.19-20 The sub-title preceding these two paragraphs is confusing: the section immediately preceding relates to disclosures not directly related to the care of the service user; the following paragraphs deal with disclosures for purposes not related to health or social care.

The paragraphs are repetitious, confusing (particularly if one hasn't already read paragraphs 5.20-5.27) and/or misleading. Consent should not be sought for disclosures that *will* be made in the public interest; rather service users might be *informed* that such disclosures are to be made.

4.2 After outlining the obligation to keep records, this paragraph suggests patients can refuse consent to have records made about their care. Records are not only kept for purposes of the patient's care; other purposes include the health or social care professional's legitimate interest in keeping records for purposes of responding to future complaints, for example. Patients can ask that no record be kept, but there is no obligation on the part of health or social care professionals to comply. Doctors would breach professional guidance (see paragraph 3f of *Good Medical Practice*). Patients can decide to refuse care in those circumstances (or they might provide false details).

4.3 I was surprised by and a little confused about the purpose of this paragraph, particularly the section on the *tendency* of EPRs to transgress traditional boundaries. EPRs are fairly ubiquitous in modern healthcare. Policies and systems to widen

access raise data protection issues, but do not on their own raise issues of confidentiality.

4.4 I wasn't sure why the specific legal rights of access are qualified in this paragraph and the preceding title by 'general'. The second sentence of this paragraph is unnecessary and should be deleted. The reference to third party information exemption should be qualified to clarify that this does not include relevant health professionals. And the alternative basis to consent (Data Protection Act 7(4)(b) – reasonable in all the circumstances) for disclosing third party information might be mentioned.

4.7 What kind of 'authority' is meant? Is this a reference to those with legitimate access to the information? Clarification would help.

4.9 The second sentence should be redrafted – it currently suggests patient data cannot be left unattended!

4.10 The reasonable satisfaction required in the second sentence is reasonable when sharing data with other professionals and agencies, but is not relevant when sharing with or at the request of service users, who can choose to share their data in any way they choose.

4.12 The first sentence might actually be clearer if 'in the possession of the holder' was deleted. Conversely, the final sentence might clarify that pseudonymised information about individuals might be linked only by those with the key or index.

4.15 Reference to electronic records might be integrated into the first sentence, allowing deletion of the final sentence, which reads as something of a non sequitur or an afterthought.

5.1-2 These paragraphs are very longwinded. A simpler alternative might be something like 'the purpose of disclosure or use of any service user information should be clear. The minimum information consistent with/proportionate to that purpose should be used or disclosed'.

5.3 This represents something of a repetition, and (with regard to the section following the points A, B and C) there are no other types of purpose: information can only be used or disclosed for care purposes (A), other health and social care purposes (B) or for purposes other than A or B (C)!

5.9-10 The middle section of paragraph 5.9 and end of 5.10 suggest that service user's express consent is required for disclosure of information to an external agency and informal carers. Is this the intention? If the disclosure is for purposes of direct patient care, it is not clear why this should be the case. If it is the intention (a deliberate policy for Northern Ireland) this should be made clear. You might wish to refer to FAQ4 in our Confidentiality FAQs.

5.12-13 This section would be better without 5.12, which suggests that it is unproblematic to take on obligations that conflict with the primary duty to the service user. 5.13 is clearer on its own.

5.15-16 These paragraphs summarise a problematic issue in a manner that might only add to readers' confusion. It confuses statutorily required disclosures with disclosures made in the public interest. While one might hope that statute would only require disclosures where the public interest required it, that might not necessarily be the case (statute is, by nature, a blunt instrument that does not usually allow for weighing of interests in specific circumstances), and it is better to make a clear distinction between the two. Paragraph 5.17 addresses the issues more clearly and 5.15-16 might be deleted. 5.15 contains some confusing drafting and the reference to RECs in 5.16 should not be confused with the remit of PIAG.

5.17 The second sentence reference to 'Secondary uses' should be to 'Secondary use disclosures'.

5.18 PIAG is not exclusively or even primarily concerned with disclosures for purposes of 'running an efficient and quality health service' if that is taken to mean administrative and financial efficiency. Many PIAG approved disclosures concern research, for example. This might be made clearer in the Code. Most disclosures for administrative, financial and health quality purposes are statutorily obliged or can be anonymised.

5.19 Penultimate bullet point: Organisations should not disclose information for secondary purposes where service users have opted out. That is not to say that health and social care organisations should comply with service users requests to destroy records, which is what the Code suggests.

5.20 The preceding title might be amended to '... related to health or social care', given that disclosures under (B), such as research which holds no prospect of direct benefit to the service users to whom the data relates, do not relate to the care of that service user.

Aren't all the examples at the end of the paragraph about protecting third parties, which is the first example?

5.21-22 Both of these paragraphs are confusing, repetitious and add little to the Code. Paragraph 5.22 in particular is circular: are there higher tests for disclosures to be ethical, or is the assessment needed the same?

5.23 5.23 is helpful, but makes no reference to a particular difficulty in Northern Ireland, namely s5 of the Criminal Law Act (Northern Ireland) 1967. This poses very real dilemmas for doctors, e.g. in providing sexual health advice to sexually active teenagers. This might be addressed head on.

5.24 The phrase 'in the absence of consent or presence of dissent' is confusing, while the paragraph as a whole (save, perhaps the final sentence) adds little.

5.25 In addition to the service user's right to privacy should be added mention of the public interest in a confidential health and social care service. What are the established formal procedures?

5.26 This paragraph adds little to the Code; and don't service users indeed become subordinate to public interests which outweigh their individual interests (and the public interest in confidentiality)?

5.27 This paragraph jars with earlier advice on the public interest in statutorily obliged disclosures. It even suggests that all statutorily obliged disclosures are ethical. Whether they are or not might be considered largely irrelevant – they have to be made.

5.28 '...in the public interest' might be deleted from the end of the second sentence or replaced with 'and the public interest in a confidential health and social care service' or similar.

Appendix 1

See comments regarding paragraph 5.20 and its sub-title with regard to the introductory section on page 25.

Flowchart A

'Is there some who has the legal authority to make the decision on behalf of the service user? (2.12)' – See comments regarding paragraph 2.12, above.

'Consider whether informing the service user about the disclosure is in their best interests' – This is not the correct test. Rather, the service user should be informed unless it would cause them serious harm.

'Also consider whether exceptionally there may be a public interest justification for disclosure' – this is an odd suggestion. If that were the justification, staff should refer to flowchart C. Such reference might encourage unclear thinking (or even deception) in seeking to justify disclosures.

There is a YES box missing towards the end of the flowchart.

Flowchart B

No doubt for purposes of brevity, flowchart B circumvents *asking* for service users' consent, which may be unhelpful.

'Proceed with the use or disclosure, making sure that the information is not kept in a form which identifies the service user unless...' – this is good advice, but irrelevant to the flowchart, which must be about the use of identifiable data. The same might be said in relation to the final box.

Flowchart C

The first box contains a double negative, which should be avoided and the subsequent choices reversed accordingly. It also suffers from the phrasing commented upon in relation to paragraph 5.20, above.

Disregarding the above, if one has arrived at flowchart C by way of flowcharts A and B, how could the answer to the first question be NO? What other uses or disclosures are there?

‘Is there a statutory basis for the use or disclosure?’ might more accurately read ‘Is there a statutory obligation to disclose?’.

The circumvention of *asking* for consent commented upon in relation to flowchart B appears here too.

There is a YES choice missing from the right hand side of the flowchart.

‘Assess on a case by case basis whether the use or disclosure is necessary...’ – isn’t this addressed in the preceding box (regarding necessity) and the final box (regarding extent of disclosure)?

‘If appropriate, make sure that the service user is informed...’ – service users should be informed unless that’s impracticable, would undermine the purpose or put someone at risk of serious harm.

Appendix 4

The numbered points present a traditional interpretation of the case of *Coco v Clark*. Point 3 in particular raises difficulties with regard to the records of deceased patients, who cannot be harmed. For an exploration of the necessity of 3 in an analysis of the common law of confidentiality, see the Information Tribunal’s decision in the case of *Bluck v Information Commissioner and Epsom & St Helier University NHS Trust* (Appeal Number: EA/2006/0090).

This analysis of the common law of confidentiality suffers from the conflation of confidentiality and privacy, there being no separate tort for the latter. As such, the sentence immediately following the numbered points jars with the penultimate paragraph.

It would be unreasonable to include a fuller analysis in the Code, but this summary is not very satisfying, which adds to the argument to delete this appendix altogether. It is difficult to imagine this appendix being of much use to health and social care professionals struggling with questions of use or disclosure of service users’ data.

Appendix 5

See earlier comments about the usefulness of this appendix. In particular, I am not clear on the purpose of the exploration of procedures for complaint prior to the enactment of the Human Rights Act (end page 35).

Appendix 6

The most relevant Schedule 3 conditions (page 38) certainly includes processing necessary for medical purposes (including preventative medicine, medical diagnoses,

medical research, the provision of care and treatment and the management of healthcare services).

In the penultimate sentence of the largest paragraph on page 38, there is reference to two consequences. What is the second?

In the following paragraph, second sentence, the reference to sensitive personal data is superfluous. That same paragraph might include a reminder that data about a deceased patient might also relate to a living person, such as the deceased person's relative (e.g. in the case of hereditary diseases), as the Information Commissioner has explained in technical guidance. A more serious concern about this part of the Code is that its focus on the DPA might leave selective readers with a misapprehension about their other legal (and ethical) duties, which are far more onerous.

Appendix 7

The reference to harm in the first paragraph should be qualified with 'serious', while the example of misuse of controlled drugs (which would certainly not always warrant disclosure) is problematic.

The range of public interests provided by Article 8(2) of the ECHR are so encompassing as to make the second paragraph superfluous.

Is the reference to 'possibility' in the third bullet point a synonym for imminence or likelihood? They are related, of course, but the latter is possibly more relevant.

The need for an 'authority' to whom to disclose in the fourth bullet point overlooks the occasional justification for disclosing to individuals, such as partners of service users with serious communicable diseases.

Should the 'possibility' reference in the fifth bullet point be qualified by a test of reasonableness or practicality?

Is it really necessary that explanation be given in writing, as required by the first of the second set of bullet points?

With regard to the final paragraph, the safety of others (not just staff) should be considered, e.g. victims of or witnesses to crime.

Appendix 8

The third paragraph makes for difficult reading. The main point appears to be that requests take all forms and should be dealt with properly, even if incorrectly labelled, and that FOIA does not allow access to data protected by the DPA.

Appendix 9 (incorrectly numbered?)

Why is the test outlined in the first paragraph limited to adults? Children can demonstrate their capacity in the same way. S66 of the Data Protection Act states

that a child shall be taken to have capacity where he has a general understanding of what it means to exercise that right. It would be odd of an adult was required to pass a higher test, which seems better suited to questions of capacity to consent to treatment.

The suggestion to postpone decisions outlined in the second paragraph should be balanced with a need not to disadvantage incapacitated adults because of such a delay. And most of the subsequent points rather repeat the first paragraph test.

I am not sure what 'strictly' adds to the third paragraph, and may be problematic with regard to parental access to their children's records.

Further Information and Guidance

The BMA's 2007 guidance on secondary uses might be referenced. Our own guidance on children and young people has been published under the title *0-18 years: guidance for all doctors*.

July 2011