The Tavistock and Portman
NHS Foundation Trust

# Freedom of Information Act 2000 disclosure log entry

## Reference
18-19379

## Date sent
26/03/2018

## Subject
GIDS Case Studies: Obtaining/Maintaining Pt Confidentiality & any reported Breaches

## Details of enquiry
a) A copy of any policy, protocol or ethical form that clinicians or researchers at GIDS must comply with/complete before publishing case studies or vignettes in academic, policy, media or other publications
b) Details of any safeguards that are in place to ensure that where pseudonymised case studies are created, the child/family involved cannot be identified through aggregation of personal details.
c) Details of any consent processes that are in place to seek informed consent from children and/or their families for such publications.
d) The number of times in the last five years when GIDS or clinicians connected to GIDS have been referred to, or referred themselves to, the Information Commissioner's Office or any ethical or research safeguarding body for issues relating to failure to protect patients' personal details in creating case studies or in any other research activities.

## Response Sent
a) A copy of any policy, protocol or ethical form that clinicians or researchers at GIDS must comply with/complete before publishing case studies or vignettes in academic, policy, media or other publications.

Please see attached to this response our Trust publication guidelines.
We also adhere to the age 6, ICO Anonymisation Code NOV2012.

b) Details of any safeguards that are in place to ensure that where pseudonymised case studies are created, the child/family involved cannot be identified through aggregation of personal details.

There are details regarding our pseudonymisation procedure in the Trust publication guidelines.
We also adhere to the age 6, ICO Anonymisation Code NOV2012.

c) Details of any consent processes that are in place to seek informed consent from children and/or their families for such publications.

Please see attached our consent form which requests consent from those we involve in research. This is given out to all young people entering the service as part of a more general patient details form.

d) The number of times in the last five years when GIDS or clinicians connected to GIDS have been referred to, or referred themselves to, the Information Commissioner's Office or any ethical or research safeguarding body for issues relating to failure to protect patients' personal details in creating case studies or in any other research activities.

We are not aware of any instances where GIDS or GIDS clinicians have referred themselves or been referred to the ICO.

# Trust Publication Guidelines

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|---|---|
| Version: | 3 |
| Approved by | Medical Director |
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# Contents

## 1 Introduction

The Trust recognises the importance of protecting the identity of patients when seeking to publish reports and other documents that relate to the work of the Trust. These guidelines provide staff, students and trainees with a framework to ensure that issues of consent and confidentiality have been fully considered and explored prior to submitting a document for publication.

The Guidelines take into account recent changes in the law on confidentiality. The Guidelines also refer staff and students to recommendations made in the ethical guidance provided by a range of professional institutions (*British Medical Association, American Psychological Association, General Medical Council, Royal College of Psychiatrists*), and by organisations dedicated to upholding standards for research ethics (*World Medical Association Declaration of Helsinki*) and good editorial conduct (*Committee on Publication Ethics, World Association of Medical Editors*).

Guidance on implementation is included in an annex.

## 2 Purspose

These Guidelines are presented to help staff and trainees consider issues of consent and confidentiality when submitting for publication articles based on, or making use of, material from clinical sessions or clinical research interviews conducted at the Trust.

These Guidelines do not exonerate clinicians and clinical researchers from keeping themselves abreast of the law, professional ethical guidance and literature in this area, as they would expect to do in all other areas of their practice.

## 3 Scope

These guidelines are to be followed by all current and past staff, students and trainees seeking to publish any work that relates to the Tavistock and Portman NHS Foundation Trust.

## 4 Format of Guidelines

The Guidelines set out the following:

- key principles summary of legislation
- summary of professional guidance

Guidelines to be followed during the preparation of material for publication.

## 5 Principles

## 5.1 Consent

The fundamental principle from which we start is that **patient consent is key** and that professional interests must not be put before those of the patient, whose best interests are the overriding consideration. This principle holds equally whether we are considering the patient's treatment (where information may be shared with the health and social care team) or where information may be used in a wider sense: research, teaching, training and so on. In the context of publication, it means that authors' career development must never override their duty of care to the patient.

### 5.2 Best interest

We recognise that clinicians and clinical researchers also have in mind the best interests of patients as a group, whose interests might well be served by accounts of clinical work with particular kinds of patients. (Indeed, this point is often made by parents who consent to publication of details of their child's treatment.) This value may potentially conflict with the best interests of the individual child.

### 5.3 Principle of effective writing

A further basic principle is that all written accounts of patients should be non-pejorative, non-gratuitous, balanced, and compassionate.
Professional jargon may sometimes offend, even if the author considers the terminology purely descriptive.

# 6 Legislation

Looking at what the law allows, the Human Rights Act includes a notion of the 'right to privacy' (in Article 8), but this in fact adds little to what UK legislation or case law already lays down. The most recent Data Protection Act (1998) strengthens the obligation of confidentiality covering the 'processing' of certain types of manual health records by widening the definition of 'processing' to include obtaining, storing and disclosing data. However, there is also a condition in the Act which allows processing where this is necessary 'for medical purposes', and it is possible that disclosure of patient information in the form of case histories for the purposes of teaching/research would fall within this 'medical purposes' provision.

The key principles of the law of confidentiality are contained in common law, that is, the decisions of judges in particular cases. Prospective authors still need to be aware of the risk of complaint by individuals in respect of defamation, negligence and breach of confidentiality. It must be remembered that patients need not show that they have sustained any damage from unwarranted disclosure to succeed in a civil action. To clarify: if the action of the patient is based on the duty of care owed in the law of *negligence*, then, for the action to succeed, *clear harm must be established*.

In such a case it would have to be demonstrated that another person identified the patient in the publication, since that would be how the harm occurred (Dimond 1995). However there is also a professional duty, recognised by most professional codes of practice, to keep confidential any information about the patient, unless the patient gives consent or unless there is a recognised legal duty to disclose. Where the duty of *confidence* is at issue, unlike the law of negligence, *the misconduct lies in the disclosure* rather than any harm that could occur or has occurred.

Researchers should be aware that whilst the opinion of a research ethics committee may assist in reaching a decision, the opinion of the committee does not constitute legal authority for disclosure; responsibility is borne by the person making the disclosure. The new Mental Capacity Act 2005, when it comes into force, will also set out a new regime with respect to research proposals involving incapacitated adults. This may be relevant to any suggested publications relating to this patient group.

## 7 Professional Guidance

The guidelines on good practice from various professional bodies are strikingly congruent. *The General Medical Council's* guidance (2000) makes clear that one has a duty to protect the patient's privacy and respect their autonomy, seeking consent wherever possible - whether or not one believes that the patient can be identified. Similarly, the UK Department of Health Guidance (1999) recommends that 'where anonymous information would be sufficient for a particular purpose, identifiable information should be omitted wherever possible'. Such anonymised information 'may sometimes be used for teaching and research'.

The chief principle of the *Royal College of Psychiatrists* ethical guidance (2006) is that a patient's written consent should be sought before the publication of case histories, whether or not the case history is anonymised. However, the guidance does also consider circumstances in which a patient's permission is not sought and notes that disclosure can only be justified when the patient can be recognised by no one (although this may still constitute a breach of confidence.)

The *British Medical Association* published lengthy guidance in 1994 taking the view that it is not necessary in general to seek consent to the use of truly anonymous information. Helpfully, it reminds us that the rules for disclosure without consent are the same whether the information relates to a patient or a colleague and that a duty of confidentiality to patients endures beyond the individual's death.

## 8 Trust Guidelines

Working from these various good practice guides and the scanty literature on the subject, the following Trust Guidelines for prospective authors have been drawn up:

• ***Avoid including patient identifiable material altogether when at all possible***. In particular when preparing vignettes particular care must be taken not to develop these from direct experience when there is the chance that a patient may be inadvertently identifiable

• ***Disclosure should be kept to a minimum necessary to fulfill the objective of the article.*** - We are aware that some commentators take the view that the literature is in danger of impoverishment by editorial reluctance to publish case reports (see Russell in Wilkinson et al 1995). This requirement is especially problematic for clinicians whose tradition enjoins them to learn by the presentation and discussion of detailed case histories (Goldberg 1997).

• ***Identifying details should only be published if the patient (or parent or guardian) gives written informed consent*** This requires that a patient who is identifiable is shown the actual manuscript to be published. The signed written consent should be submitted with the manuscript. There is no question that this is a tough requirement that would bar the publication of certain case reports that would in the past have been permitted.

• ***If patient consent has been refused, then publication of the material in a format that would potentially identify the patient MUST not proceed. .***

• ***Publication of detailed case reports can only be justified if the case report is of fundamental significance***. This is obviously a matter of judgement about what may turn out to be a clinically important observation or innovation. There is some risk that less senior and less self-confident authors might be discouraged from seeking publication on these grounds.

• ***All identifying details should be omitted if they are not essential The material should be further disguised so that none of the individuals involved could recognise themselves. Some material that is particularly distinctive should be omitted or aggregated*** This could involve changing ages, ethnicity, location, gender of individual children or siblings etc. as long as such disguise does not affect the overall sense of the narrative. (A thoughtful discussion of approaches to 'balancing scientific integrity with patient anonymity' can be found in the notes to contributors of the International Journal of Psychoanalysis.)

• ***Patient consent to publish should be sought whenever possible, even if the data are anonymised*** This represents a significant change in the emphasis over the last ten years or so, and can be seen to represent an important shift in the way issues of entitlement and authority are negotiated between clinician and patient. It may be considered that seeking consent many years after the clinical work is completed would work against a patient's best interest

(especially in the case of a child), if the contact were likely to unhelpfully re-open issues related to a therapeutic contact that had ended. It can certainly be argued – especially where transferential issues are taken in to account that the process of asking for consent might be detrimental to the patient. This concern underlies the view of some professional organisations such as the British Psychoanalytic Council, or journals such as the International Journal of Psychoanalysis and the Journal of Child Psychotherapy, that requesting permission to publish from the patient is advisable where this is possible or clinically appropriate.

• ***Capacity to give consent should be made on a case by case basis: where a patient is capacitated in any sense then his or her consent should be obtained.*** For some minors, for people with severe incapacitating mental illness and for dead patients, consent should be obtained from relatives or others, best interest must be paramount, and any previously expressed views or objections should be taken into account. Thought should be given to that possibility that, in any particular case, asking for parents' permission to publish risks prejudicing the child's right to confidentiality; the best interests of the child and parent may not be identical.

• ***The above and criteria apply to ALL publication formats*** Publication will normally occur in one, or both of two main categories of format: 'hard copy' publication in journals, books or other communication media and electronic publication. . An estimate of 'likelihood' that a patient will access some forms of publication and not others is not a proper criterion for assessing suitability for publication.

## 8.1 Consideration of Cases in which not all of the General Principles Apply

Authors may find themselves considering circumstances in which not all the guidelines set out above can be applied, but there is still a wish to publish papers or other communications containing clinical material relating to people who are, or who have been, patients of the Trust. There may also be cases where the key principles are seen to be in conflict. This section offers guidance on such circumstances.

### 8.1.1 Consent has not been obtained

Where consent has not been sought on good grounds, or has not been obtained (but has not been refused), and all the other guidelines can be applied to the written material, the author may still wish to consider publication. An author may, for example, consider that publication will contribute to the strengthening of the knowledge base for future patients. Or an author may believe that seeking consent (perhaps after many years) may unnecessarily perturb or distress the patient.

### 8.1.2 Full anonymisation is difficult to achieve

Long clinical case reports present the most challenges in achieving comprehensive anonymity. Lengthy and detailed clinical case reports do not easily accommodate comprehensive anonymity, even where all the usual steps have been taken. Detailed reports of dreams, relationships, and life circumstances may mean that the material may still be identifiable by, at least, the patient. If the patient gives consent under these circumstances then publication can proceed safely. If consent has not been sought or obtained, then publication of material that might be recognised by the patient enters a legal and ethical 'grey area'. This area is framed by the clause in the 1998 Data Protection Act that allows disclosure of information where this is necessary "for medical purposes", a catch-all provision that includes medical research.

Thus it is arguable that publication can be justified in cases where either consent has not been sought or obtained, on good grounds, and/or full anonymisation is impossible to achieve without severe loss of research relevance. However, the Trust takes the view that where such circumstances occur, ***publication should only be considered in cases where there is a clear public interest rationale for publication on the grounds that significant new knowledge will be imparted to the professional and scientific community as a result, with potential benefit to the wider patient group***.

This criterion would, therefore, exclude reports – however sophisticated and well-argued - that contribute only a marginal or unclear contribution to the state of knowledge. If publication is to be considered in cases where consent has not been obtained, and/or anonymity cannot be easily achieved, then the risk of complaint or litigation should the patient read the publication, must be assessed as part of the decision to publish or not publish.

If there is real concern, then authors should seek legal advice. In point of fact, civil actions for breach of confidentiality are rare. When decisions that rest on clinical judgement are tested in court, judgement is likely to rely less heavily on law itself as on whether the relevant laws, guidelines and ethical codes - as well as the issues relating to patient sensibilities vs. the greater good in publication of the material - have been properly considered and properly documented. Since there is little in the way of precedent due respect to guidelines; codes of principle; opinions of ethical committees etc; – even though not legally binding; – will be essential in helping to establish favorable precedent.

The Trust recognises that public, as well as legal, opinion shifts over the course of time and while the broad parameters for good decision-making in this area can be specified in a document such as this, Trust staff should also be prepared to engage in further thinking and debate over them, both in the context of periodically reviewing the guidelines and in reviewing of individual cases where authors are uncertain how to

proceed.

In cases falling into these 'grey' areas, that cannot easily be resolved by reference to the guidelines, the Trust recognises the need for a way in which these cases can be discussed and the matter adjudicated. It is acknowledged that where values conflict, recourse to ethical rules and guidelines does not always resolve the issues. In such cases, reliance on 'good process' for effective decision- making appropriate (Fulford 2005).

It is therefore proposed that the Trust establish a Publication Ethics Committee to offer consultation to prospective authors (employed by, or students in, the Trust) who are concerned over ethical issues related to publication of papers containing reference to clinical material or patient information.

## 9 Process for monitoring the Effectiveness of the Guidelines

These guidelines will be monitored by exception to the Chief Executive and Medical Director. All supervisors are expected to ensure that any documents submitted by trainees fulfil the guidelines for good practice set out in this document.

## 10 References


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## Further advice and guidance for clinicians

# The inclusion of clinical material relating to Trust clients in publications by Trust staff

**Summary**

*1. Seeking patient consent to publish clinical material is widely regarded as good practice. Even where the material has been anonymised, seeking consent is generally advisable.*

*2. If patient consent has been sought and refused, publication should not go ahead.*

*3. Identifying details should only be published if the patient (or parent or guardian) gives written informed consent. This requires that a patient who is identifiable is shown the actual manuscript to be published. (The written consent should be submitted with the manuscript.)*

*4. With respect to minors, asking for parents' permission to publish risks prejudicing the child's right to confidentiality; the best interests of the child and parent may not be identical.*

*5. For some minors, for people with severe incapacitating mental illness and for dead patients, consent should be obtained from relatives or others; best interest must be paramount, and any previously expressed views or objections should be taken into account*

*6. Publication of patient details, even where consent has been given, should be kept to a minimum necessary to fulfil the objective of the article.*

*7. The same principles and criteria apply to all publication formats, whether 'hard copy' publication in journals, books or other communication media, or in electronic publication. An estimate of 'likelihood' that a patient will access some forms of publication and not others is not a proper criterion for assessing suitability for publication.*

*8. There may be some circumstances where the clinician considers that publication would be in the interests of the wider patient and professional group - embodying a clear public interest - but where requesting consent from the patient would be clinically inappropriate.*

*In such circumstances the prospective author must give due thought to the considerations outlined in this document.*

*9. If publication is to be considered in cases where consent has not been obtained, and/or anonymity cannot be easily achieved, then the risk of complaint or litigation should the patient read the publication, must be assessed as part of the decision to publish or not publish.*

**Introduction**

This discussion document is presented to help staff and trainees consider issues of consent and confidentiality when submitting for publication articles based on, or making use of, material from clinical sessions or clinical research interviews when the people being written about are, or have been patients of the Trust.

It is now widely agreed that patient consent to publish should be sought whenever possible, even if the data are anonymised. This is a significant change in emphasis over the last fifteen years or so, and represents an important shift in the way issues of entitlement and authority are negotiated between clinician and patient.

Long and detailed clinical case reports present the most challenges in achieving comprehensive anonymity. Even when steps have been taken to disguise the reported client and his or her circumstances, detailed reports of relationships, dreams or life circumstances may mean that material is identifiable by, at least, the patient.

However, we are aware that some commentators take the view that the literature is in danger of impoverishment by editorial reluctance to publish case reports (see Russell in Wilkinson et al 1995). This requirement is especially problematic for clinicians whose tradition enjoins them to learn by the presentation and discussion of detailed case histories (Goldberg 1997).

The document takes into account a range of legal considerations. It also draws on recommendations on ethical practice provided by a number of professional institutions (*British Medical Association, American Psychological Association, General Medical Council, Royal College of Psychiatrists*), by reputable psychotherapy journals, and by organisations dedicated to upholding standards for research ethics (*World Medical Association Declaration of Helsinki*) and good editorial conduct (*Committee on Publication Ethics*).

Taking note of this document does not exonerate clinicians and clinical

researchers from keeping themselves abreast of the law, professional ethical guidance and literature in this area, as they would expect to do in all other areas of their practice.

**Key Principles**

We have a fundamental duty of care to our patients. In discharging our duty, we usually assume that communication of certain patient-related information is necessary; including discussion with the referrer and GP, and that this can be done without consent (except when consent to the latter is withheld).

However, the principles of patient confidentiality and patient consent are also key. Patients coming for help have an expectation of confidentiality and the expectation that any disclosure of confidential material will be with their consent. This holds equally whether we are considering the patient's treatment, or where information may be used in a wider sense: research, teaching, training and so on.

At times clinical researchers and authors may have in mind the best interests of patients *as a group*. And it may seem that the interests of the group are served by accounts of clinical work with particular kinds of patients. (Indeed, this point is often made by parents who consent to publication of details of their, or their child's, treatment.) But this value may potentially conflict with the best interests of the individual patient.

A further key principle is that all written accounts of patients should be non-pejorative, non-gratuitous, balanced, and compassionate.
Professional jargon may sometimes offend even if the author considers the terminology purely descriptive.

When submitting for publication articles based on, or making use of, material from clinical sessions or clinical research interviews when the people being written about are, or have been, patients of the Trust, professional interests must not be put before those of the patient. In the context of publication, it means that authors' career development must never override their duty of care to the patient.

**What the law allows**

*'It is important to note that the ethical, professional, contractual and legal positions on confidentiality are complex. For example, the legal responsibilities in respect of confidential information cannot be gleaned from common law and statute alone.'* (BMA 2009)

The law in this area is not always clear and is subject to interpretation (see Hale 2003). The *Human Rights Act* (1998) includes a notion of the 'right to privacy' (in Article 8), but this in fact adds little to what UK legislation or

case law already lays down. The *Data Protection Act* (1998) strengthens the obligation of confidentiality covering the 'processing' of certain types of manual health records by widening the definition of 'processing' to include obtaining, storing and disclosing data. However, there is also a condition in the Act which allows processing where this is necessary 'for medical purposes'. In the case of duty of care, this would include discussion with colleagues for allocation, referral and CPD and would include minimum necessary information for contract purposes.

It is also possible that the use of limited patient information (indeed the minimum required) in the form of case histories for the purposes of teaching/research would fall within this 'medical purposes' provision. The Caldicott guidelines (1997) would support this use.

Altogether, these laws in the UK effectively imply the need to alter, anonymise or aggregate patient data for teaching and research purposes where possible without loss of value.

However, the important legal considerations relevant to issues of consent and confidentiality are actually contained in *common law* - that is, law based on previous judgments in court and taking into account the opinion of other members of the relevant professions. Whilst various interpretations of the common law may be possible, there is widespread acceptance that it reinforces the view that information may be disclosed with patient consent, where there is an overriding public interest or where the law requires it.

Individual patients might make a complaint against an author in respect of defamation, negligence or breach of confidentiality. If the action of the patient is based on the duty of care owed in the law of *negligence*, clear harm must be established for the action to succeed. In such a case it would have to be demonstrated that another person identified the patient in the publication, since that would be how the harm occurred (Dimond 1995).

However, where the duty of *confidence* is at issue under common law (the duty to keep all information confidential about the patient, unless the patient gives consent or unless there is a recognised legal duty to disclose), the misconduct lies in the disclosure itself and not in any harm that could occur or has occurred. To clarify: *patients need not show that they have sustained any damage from unwarranted disclosure.*

(Researchers should be aware that while the opinion of a research ethics committee may assist in reaching a decision, the opinion of the committee does not constitute legal authority for disclosure; responsibility is borne by the person making the disclosure.)

**The law and 'vulnerable' patients**

Publishing clinical material derived from work with 'vulnerable' groups - children under the age of 16 and adults with incapacity – requires particular consideration.

The *Mental Capacity Act* (2005) sets out a regime with respect to participation in research with incapacitated adults and minors which may be relevant to publication of clinical reports. Under the Act, all people aged 16 and over are presumed in law to have the capacity to give or withhold their consent to disclosure of confidential information, unless there is evidence to the contrary. A patient who is suffering from a mental disorder or impairment does not necessarily lack the capacity to give or withhold their consent.

The Act deems it good ethical practice to seek the views of patients, even in situations where it is a legal representative, rather than the patient, who gives consent. The professional is expected to carefully consider the explicit wishes of any patient, to the extent that they are able to assess the information provided and form an opinion. Any sign of distress or indication of refusal should be considered as implied refusal. The vulnerable participant may be asked to sign an 'assent' form to record the outcome of the discussion, although this has no legal validity.

With respect to minors (aged under 16), the consent of a parent or a person with parental responsibility is required, even if the minor is considered competent according to the Fraser Guidelines (previously referred to as 'Gillick competence'). If a competent child consents for himself or herself, a parent cannot over-ride that consent. Legally, a parent can consent if a competent child refuses, but such a serious step will rarely be ethically appropriate. If the child is not willing to consent, ethically this may over-ride the legal consent given by a parent.

Young people aged 16 and 17 are considered in law to be able to consent for themselves.

**Professional Guidance**

The guidelines on good practice from various professional bodies are strikingly congruent. The *General Medical Council's* guidance on Confidentiality (2009) makes clear that one has a duty to protect a patient's privacy and respect their autonomy, and that, where publication is concerned, one should seek consent wherever possible, whether or not one believes that the patient can be identified in the content. However, while confidentiality is an important duty, it is not deemed absolute by the

GMC. Personal information about patients may be disclosed if it is required by law, if the patient consents or if it is justified in the public interest.

The UK Department of Health Guidance (1999) recommends that 'where

anonymous information would be sufficient for a particular purpose - including teaching and research - identifiable information should be omitted wherever possible'. The Caldicott principles (1997) embody a comparable view.

Similarly, the chief principle of the *Royal College of Psychiatrists* ethical guidance (2010) is that a psychiatrist contemplating publishing should seek the patient's written consent (even where the case history is to be anonymised). If patient consent is not practicable, the material must be anonymised.

The *British Medical Association* guidance on Confidentiality (2009) also emphasises the need to seek consent to the use of information. Helpfully, it reminds us that the rules for disclosure without consent are the same whether the information relates to a patient or a colleague, and that a duty of confidentiality to patients endures beyond the individual's death.

Seeking consent many years after the clinical work is completed might be seen to work *against* a patient's best interest (especially in the case of a child), if the contact were thought likely to unhelpfully re-open issues related to a therapeutic contact that had ended. It could be argued – especially where transferential issues are taken in to account – that the process of asking for consent might be detrimental to the patient. This concern underlies the view of some professional organisations, such as the *British Psychoanalytic Council,* that the patient's permission to publish clinical material should be sought where this is possible *or 'clinically appropriate'*.

**Editorial Guidance**

*The International Journal of Psychoanalysis* and *The Journal of Child Psychotherapy* expect authors to take considerable trouble with protecting the patient's privacy through anonymisation and disguise. They recommend that, *where possible and appropriate*, the permission of the patient should be obtained, but they stop short of demanding that the patient's agreement to publish be obtained in all cases.

**Entering the 'grey' areas**

If consent to publish clinical material has *not* been obtained, then publication of material that might be recognised by the patient enters a legal and ethical 'grey area'. As we have seen, this area is framed by the clause in the 1998 *Data Protection Act* that allows disclosure of information where this is necessary "for medical purposes", a catch-all provision that includes medical research.

If publication goes ahead in cases either where consent has not been sought, on good grounds, and/or where full anonymisation is impossible to achieve without severe loss of relevance, the justification for publishing

needs to be clearly articulated – e.g. that such material has a demonstrable research, educational and communicative value for the profession. This would be is a public interest rationale, on the grounds that publication will impart significant new knowledge to the professional and scientific community, with potential benefit to the wider patient group. (Ironically, it may be that the greater the value of the material to be published, the greater the concomitant risk of the patient(s) seeing it.)

This kind of rationale necessarily excludes reports – however sophisticated and well-argued - that contribute only a marginal or unclear contribution to the state of knowledge.

If publication is to be considered in such cases, then the risk of complaint or litigation, should the patient read the publication, must be assessed as part of the decision to publish or not publish. If there is real concern, then authors should seek legal advice. Civil actions for breach of confidentiality are actually rare. When decisions that rest on clinical judgement are tested in court, judgement is likely to rely less heavily on law itself as on whether the relevant laws, guidelines and ethical codes (as well as the issues relating to patient sensibilities *vs.* the greater good in publication of the material) have been properly considered and properly documented.
Being governed by common law, any legal judgement will rely in part to on the judgement of the author's peers. Since there is little in the way of precedent, due respect to guidelines, codes of principle, opinions of ethical committees etc – even though not legally binding – will be essential in helping to establish favourable precedent.

**The T&P Trust Publication Ethics Committee**

In cases falling into these 'grey' areas, that cannot easily be resolved by reference to the guidelines, the Trust recognises the need for a way in which these cases can be discussed and the matter adjudicated. It is acknowledged that where values conflict, recourse to ethical rules and guidelines does not always resolve the issues. In such cases, reliance on 'good process' for effective decision-making is appropriate (Fulford 2005).

It for this reason that the Trust has established a Publication Ethics Committee to offer consultation to prospective authors (employed by, or students in, the Trust) who are concerned over ethical issues related to publication of papers containing reference to clinical material or patient information.

The Trust recognises that public, as well as legal, opinion shifts over the course of time and while the broad parameters for good decision-making in this area can be specified in a document such as this, Trust staff should also be prepared to engage in further thinking and debate over them, both in the context of periodically reviewing the guidelines and in reviewing of individual cases where authors are uncertain how to proceed.

**References**

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**Consent for follow-up and dissemination of patient info**

In order for us to learn more about the needs of young people with gender dysphoria and to be able to offer the best possible service we conduct various research projects within our service.

We sometimes use anonymous material in books and articles or in presentations to support the learning and understanding of gender development in young people.

Sometimes it is helpful for us to follow people up after they have left the service so that we can find out how they are doing.

| I give my consent for anonymous material relating to my treatment at the Gender Identity Development Service to appear in publications and presentations relating to counselling and psychotherapy. | |
|---|---|
| ☐ | **Yes** |
| ☐ | **No** |

| I give my consent to be followed up by the Gender Identity Development Service in the future. | |
|---|---|
| ☐ | **Yes** |
| ☐ | **No** |

| Name of young person | Date | Signature |
|---|---|---|

| Name of parent | Date | Signature |
|---|---|---|