Copying letters to patients – Child and Adolescent Mental Health Services

Background and legal framework

- NHS Plan 2000 – rights and benefits argument. Patients have a right to receive letters about them
- Data Protection Act 2018 – right to request access
- Electronic records and safe haven procedures – patients will be able to read their notes via safe websites
- Disability Discrimination Act 1995 / 2005 – records must be accessible in a form suitable for the disabled

In general

- All letters from one clinician to another should be copied to patients or their parents/guardians including: referrals to social services, letters to housing, discharge summaries, not EEG/blood results etc. – if still under investigation for a disorder, general updates, discharge summaries

- Some families want some information kept confidential from other professionals e.g. may not want personal history shared with school/G.P.

- Who has parental responsibility to be regularly checked, especially for unmarried fathers and when the Local Authority has authority

- Young children cannot consent to receiving copies of letters. It is the parents right to have the copies of letters

Aim

- Improve patients knowledge of condition and treatment
- Improve communication between patient and clinician
- Increase patient’s ability to share in decision making
- Patients feel listened to, involved, empowered. Patients remember the session
- Improved compliance
- Health promotion
- Treatment outcomes are generally improved
- Parents see selves as part of the caring team and generally DO want letters
- Reinforces and confirms the information given in discussion with the patient in the consultation
Disadvantages

- Inappropriate people read the letter e.g. child/shared letterbox.
- The information is too stark and cold
- Anxiety over jargon
- Some parents tend to worry/feel criticised by letters
- Amendments to letters are negotiated

Good Practice

- No surprises/new information. (Give patient a copy of the letter after its contents have been discussed face to face)
- Patient’s decision about whether or not they wish to routinely receive copies of letters is recorded in the notes – part of the discussion about ‘what will happen next!’
- No subjective statements
- Technical jargon is explained (in brackets or face to face)
- Local Authority looked after children – best practise suggests letter goes to the parent, social worker and foster carer
- Facts, no speculating
- Check only one person with that name resides at the address

Uncertainty over diagnosis / what is happening – minute all possibilities in a letter and copy to patient, or use telephone, or seek agreement to write separately to clinician. Note it is a possible hypothesis given the information you have.

Family Dynamics – couch it in terms of the impact of the illness rather than the failure of parenting – ‘parents are finding it very hard to ensure that ……..’

Don’t Copy

- Where it may cause harm or be injurious to a person’s mental health
- ‘Fabricated illness or child protection – follow guidance from ‘Working Together to Safeguard Children’ and ‘Fabricated Illness by Carers’ – Royal College of Paediatrics
- If it is advisable and in the child’s best interest to withhold the notes. ‘Minutes of the Meeting’ can be offered instead
- If patient doesn’t want a copy e.g. privacy issues for young people
- Where the letter gives information about a third party
- Where special safeguards for confidentiality are needed
COPYING LETTERS TO PATIENTS POLICY - CP34

- Where the clinician makes comments about another clinicians care/treatment practice

- If there are concerns about Munchausen’s by Proxy for e.g., these letters between clinicians would not be copied to the carer. State ‘I have not copied this letter to the family because I have concerns……’

- Unmarried fathers – have to have agreement of the mother to receive copies of the letters about the child

- These letters can however be reviewed in the future if concerns are unfounded – so the clinician needs to have an eye to the future when sharing concerns

- 16 and 17 years make their own choice re letters (letters may need to be at clinic rather than sent to home address) for reasons of privacy

- Younger children need to be assessed as Gillick competent

Pilot Study (Great Ormond Street)

20% of patient details – address, language, person with parental responsibility was inaccurate – need for regular checks

97% of parents wanted to have letters copied to them

Family therapists used it as part of a therapeutic intervention

89% of over 11’s wanted a copy of a letter

50% of families would show the letter to an under 16, 50% would wait until their child was over 16

Many parents open their child’s correspondence even if addressed to the child

Many young people read their parents correspondence

Young people disliked ‘Mr and Mrs Blogg and Jo’ – and wanted their copy addressed to them. Those over 16 felt this was their ‘right’.