Best practice recommendations for eating disorder services accepting self-referral

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Summary

Treatment for an eating disorder tends to become increasingly difficult as illness duration lengthens, resulting in the individual spending more time unwell, having a worse prognosis, and increasing distress for both the individual and their loved ones. Multiple barriers to treatment exist and must be addressed in order to ensure people can access the appropriate evidence-based treatment quickly.

Self-referral for specialist assessment removes a significant barrier by allowing individuals to refer themselves or their loved one to the local eating disorder service, so avoiding the need for the individual to seek referral from their general practitioner.

Self-referral for specialist assessment has been recommended for all Welsh eating disorder services, and must be offered by all children's and young people's services in England by March 2021. Despite this and in the face of the advantages of self-referral, the proportion of services which accept self-referrals remains low.

A 2017 investigation into self-referral across UK eating disorder services for children and young people found that 50 services (49.0%) stated that they accepted self-referral. A number of these placed restrictions on who could self-refer, based on factors such as the individual's age or diagnosis. A follow-up investigation in January 2020 found that self-referral was accessible in only 33 services (33.7%) for children and young people, and nine services (11.4%) for adults. When compared against proposed best practice standards in the provision, promotion, and accessibility of self-referral, four services (4.1%) for children and young people and 0 services for adults met the proposed standards.

This paper outlines the advantages of self-referral, presents the results from the investigation into availability and access, and recommends best practice standards for services introducing self-referral.

Why self-referral is important for eating disorders

The early stages of an eating disorder are a potentially critical period for reducing the duration of the illness (1) and treatment tends to be less effective as illness duration increases (1–7). Therefore, delays in referring people with eating disorders can lead to longer duration of illness and worse prognosis.

General practitioners (GPs) are normally the first medical professional an individual will encounter when they seek support and advice for concerns about their eating behaviours or other symptoms of an eating disorder. GPs commonly act as the 'gatekeeper' to psychological services, meaning that people must receive a referral from them in order to access specialist treatment. Despite this, GPs have consistently been found to have substantial gaps in their knowledge about eating disorders (8–13) with GPs themselves expressing a lack of confidence in recognising an eating disorder (9–11).

This lack of knowledge means that people with an eating disorder are commonly not receiving an immediate referral to a community eating disorder service (as recommended by the NICE guidelines (14)), and thereby face delays in accessing treatment.

In a 2017 survey by Beat (15), only 14% of people who sought help for an eating disorder were referred for an assessment within four weeks of their first GP visit. On average people waited 11 weeks between first seeing their GP with the symptoms of an eating disorder and being referred for treatment, with females being referred faster than males (10 weeks compared to 28 weeks) and children and young people being referred faster than adults (7 weeks compared to 15 weeks). If people were instead able to self-refer to an eating disorder service, this would eliminate this delay in making a referral and would allow them to receive treatment more quickly.

Policy context

The importance of self-referral is recognised by NHS England's Access and Waiting Standards for Children and Young People (16) which states that by March 2021 services should provide access to community eating disorder treatment for CYP through self-referral. Similarly, the Welsh Government's 2019 Eating Disorder Service Review (17) states that eating disorder services should accept self-referral. No equivalent recommendation has yet been made by the NHS in Scotland or Northern Ireland.

Outside Wales, there is no requirement for services to accept self-referral from adult service users, although the appendices to NHS England's Guidance for commissioners and providers of adult services (18) suggest that, for existing adult service users, self-referral back to the service should be available and promoted to service users and their carers.

Best practice for self-referral for a specialist eating disorder assessment

Due to inconsistencies surrounding the accessibility and availability of self-referral across the UK, the following best practice standards are proposed. These have been developed following expert clinical guidance and through discussions with service users about their experiences of the referral process.

All providers of eating disorder services should:

1. Accept self-referrals for specialist assessment from service users.
2. Accept referrals which are made by a parent, partner or other carer on behalf of a service user, with the permission of the service user if they are aged 16 or over.
3. Ensure that information on how to self-refer can be easily found and readily understood by service users and their family/carers.
4. Design forms and questionnaires used in the referral process to be easily understood and quickly completed.
5. Ensure self-referrals are treated according to the same protocols and principles as are applied to referrals made by health and medical professionals.

Difficulties in availability and accessibility of self-referral

Availability of self-referral across the UK – December 2017

A Freedom of Information (FOI) investigation by Beat in 2017 (see Appendix for methodology) found that the provision of self-referral by NHS Children and Young People (CYP) eating disorder services in the UK is incomplete and inconsistent. The FOI request found that only 50 eating disorder services for CYP (49.0%) accepted self-referral. When asked whether the service had any restrictions around who would be accepted following self-referral, 19 of these services (38.0%) admitted restrictions, for example, due to age or diagnosis.

In England, 26 services (34.7%) responding to the FOI request stated that they did not yet accept self-referral, with 12 services (46.2%) reporting that they had no plans to do so despite the 2021 deadline. Only a minority (15.4%) of services providing treatment for adults in England were found to accept self-referral, with some restrictions on availability similar to those found in services providing treatment for CYP (Table 1).

Outside England, only one service (3.7%) reported that it accepted self-referrals for CYP (Table 1).

Table 1. Results from the December 2017 Freedom of Information Request – CYP services only

	Number of services that responded	**Services stating that they accepted self-referrals**		**Of which, services that stated they had no conditions for self-referral**		**Services stating that they did not accept self-referral**	
	n	n	**%**	n	**%**	n	**%**
England	75	49	**65.3%**	30	61.2%	26	**34.7%**
Northern Ireland	3	0	**0**	0	0	3	**100%**
Scotland	17	1	**5.9%**	1	100%	16	**94.1%**
Wales	7	0	**0**	0	0	7	**100%**
Total UK	102	50	**49.0%**	31	62.0%	52	**51.0%**

Availability of self-referral across the UK – January 2020

To update these findings and expand on them in relation to services offering treatment to adults, an investigation into the availability of self-referral via eating disorder services' websites was conducted in January 2020 (see Appendix for methodology). Of the 98 services identified across the UK that provided treatment for CYP diagnosed with an eating disorder (noting some changes to services since the 2017 FOI), 33 services (33.7%) were found to accept self-referrals. Fifteen services (30.0%) which informed the 2017 FOI that they accepted self-referrals were found not to do so during the online search in January 2020.

Of the 79 services across the UK identified as providing treatment for adults diagnosed with an eating disorder, nine services (11.4%) were found to accept self-referrals. A breakdown of the results can be found in Table 2.

Table 2. The number of services found to accept self-referrals in January 2020, across the UK.

	Number of services found to accept self-referrals		**Number of services accepting self-referral in a way which meets the proposed standards**	
	CYP	Adult	CYP	Adult
England	32 (44.4%)	8 (15.1%)	4 (5.6%)	0
Northern Ireland	0	0	0	0
Scotland	1 (7.1%)	1 (7.1%)	0	0
Wales	0	0	0	0
Total UK	33 (33.7%)	9 (11.4%)	4 (4.1%)	0

Accessibility of self-referral across the UK

In services where self-referral was found to be available in the January 2020 investigation, the accessibility of this self-referral process was compared against the proposed best practice standards (excluding standard five). The relevant standards on communication were deemed to be met if the following were in place:

- The service's website should provide clear and easily-found information on:
  1) how a service user can self-refer into the service
  2) who to contact if they have any questions about self-referral
  3) what to expect after making a self-referral (including expected timeframes)
- Information on self-referral should be easily found via the service's own website's file structure and search function, as well as directly from the main internet search engines
- There should be more than one way to self-refer, for instance, online form, telephone call, downloadable form to be emailed
- Information on self-referral is also available through other sources – e.g. hospital information desks, GP surgeries and local schools
- The compulsory information collected by the initial self-referral is limited to:
  1) basic personal information such as name, date of birth and home address
  2) GP name and address
  3) a short description of behaviours/reason for the self-referral
  4) contact details for the person making the referral
  5) information about any other illnesses that the person would like to share.

Results found that across all the services that were identified in the UK, only four services (4.1%) for CYP and 0 services for adults met all the proposed standards. All four (100%) of these CYP services were in England.

When considering the standards, no individual standard was met by all services. The greatest compliance was found in relation to permitting carers of CYP to make referrals and indicating how they can ask further questions of the service (Table 3). In the majority of cases, a surplus of information was required for the self-referral process compared to that deemed necessary to meet the best practice standards.

Table 3. The number of services found to meet each proposed best practice standard, compared to those found to accept self-referrals in January 2020.

	Number of services found to meet each best practice standard*	
	CYP	Adults
Referrals accepted from carers	27 (81.8%)	3 (33.3%)
How to contact the service with questions is clear	32 (97.0%)	5 (55.6%)
Next steps following self-referral is clear	12 (36.4%)	2 (22.2%)
There is more than one way to self-refer	10 (30.3%)	2 (22.2%)
Referral requires only information that is necessary and readily available	5 (15.2%)	0

*if compliance was not evident from information provide on the service website, this was recorded as not meeting the standard.

Conclusion

Self-referral for specialist assessment removes a significant barrier to accessing treatment. However, it is commonly unavailable to individuals seeking treatment for an eating disorder across the UK. An investigation in early 2020 found that the option to self-refer into services for CYPs was only available and accessible from the perspective of a service-user in about a third of services, despite FOI results in 2017 suggesting a higher number of services accepted self-referrals. This is in spite of guidance from NHS England that requires services to accept self-referral for CYP by 2021 (16), and guidelines from the Welsh Government Review stating that all eating disorder services should accept self-referral (17). Availability of self-referral for adults is much lower, with just over 10% of services found to accept self-referral.

Acknowledging that unnecessarily complicated processes may make self-referral effectively unavailable, the accessibility of the self-referral process offered by services was assessed against proposed best practice standards. When compared with these standards, no adult services and only 4% of CYP services were found to provide functional self-referral. In light of these findings, Beat encourages all NHS Trusts and Health Boards to ensure that self-referral is optimally available and accessible to people of all ages and eating disorder diagnoses. Through removing some of these barriers to seeking help, this will allow individuals to receive a quicker assessment by a specialist eating disorder service, and allow access to the appropriate support earlier.

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Appendix: An investigation into the current state of self-referral into eating disorder services across the UK

Methodology

December 2017

In order to investigate the number of services which accepted self-referral, Beat sent a Freedom of Information Request (FOI) in December 2017 to all 53 UK Trusts and Health Boards providing eating disorder services for CYP. This FOI request asked whether they provided access to the service via self-referral. Noting that NHS England's Access and Waiting Standards for Children and Young People (16) requires services to accept self-referral by 2021, a follow-up question was sent to the 26 services in England that did not accept self-referrals, to enquire about plans to implement this.

January 2020

In recognition that services may offer self-referral but that this is only useful if the process is fully accessible to and understood by the potential service user, Beat investigated the availability and accessibility of self-referral from the perspective of a service user or their loved one in January 2020. The websites of all known NHS eating disorder services in the UK (98 services offering treatment to CYPs and 79 services offering treatment to adults) were identified via the Google search engine. A route to self-referral was sought, using both Google and each website's own search function. Those services found to be offering a form of self-referral were assessed against recommendations made by Beat's Clinical Advisory Group.