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# **Klinefelter's Syndrome Treatment Satisfaction Survey**

## **Executive Summary for the Klinefelter's Syndrome Association**

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The logo for 'eXtra' features the word 'eXtra' in a blue, sans-serif font. The letter 'X' is significantly larger and bolder than the other letters, and it has a gradient from light blue at the top to dark blue at the bottom.

## **Executive Summary**

### **Aim**

At the request of, and in collaboration with the Klinefelter's Syndrome Association Committee, we undertook a survey to explore both KS-related treatment experiences, and levels of satisfaction with service provision from both healthcare professionals (HCPs) and the Klinefelter's Syndrome Association (KSA). Our aim was to identify areas where improvements to treatments and services may be of benefit to adult men living with Klinefelter's Syndrome (KS).

We did this by:

- Gathering information relating to experiences of treatment and a variety of health care provision; and
- Reviewing the support offered by the Klinefelter's Syndrome Association.

### **How we did it**

In collaboration with the KSA Committee, we developed a Treatment Satisfaction Survey. The first version of the survey was piloted at the KSA Annual Conference in 2010, where it was completed by six individuals. These early participants provided extremely useful and valuable feedback on necessary changes to the structure of the survey and the content of the questions. Based on this, further amendments were made and agreed with the KSA Committee, and a final version of the satisfaction survey was produced.

The final version of the Treatment Satisfaction Survey had seven sections. These were as follows: 1. demographic information (gender, age, ethnicity, living arrangements and employment status); 2. medical background (KS-related symptoms and aspects of the diagnostic process); 3. treatment information; 4. managing the condition; 5. access to information; 6. KSA services; and 7. open-ended questions (e.g. advice to others, and recommendations for existing or new services).

Two-hundred and fifty-nine members of the KSA were contacted by post and invited to complete the satisfaction survey. Seventy-five people responded and returned completed questionnaires, giving a response rate of 29%.

## Conclusion & Summary of findings

This study has uncovered several areas where improvements to health care provision seem to be necessary in order to better meet the needs of individuals with KS. These are summarized below.

- Individuals with KS can experience a wide range of symptoms. As a result of this, many different HCPs are involved in both diagnosis and the care of individuals with KS. HCPs require greater knowledge of the symptoms of KS, so that speed of diagnosis can be improved.
- Individuals reported problems with sleep, appearance issues, social distress and sexual problems. Some KS-related symptoms seem to be age-related (osteoporosis, and some aspects of sexual functioning).
- Acquiring a diagnosis of KS can take a long time, requires persistence, and may involve many GP appointments.
- Participants were generally satisfied with the attitudes of HCPs towards them and their condition. However, it was clear that certain HCPs (GPs in particular) may need more training to enable them to better understand and manage the care that men with KS require.
- While 82% of participants in this study expressed a general desire to be involved in treatment decisions only 46% reported working collaboratively with their consultant.
- A high percentage of participants (69%) understand their treatment options, but 42% feel they are not given a choice of treatments. Dissatisfaction with KS-related medication was expressed by 18% of participants.
- Where men with KS are provided TRT, they seem to be on a particular brand or form for extended periods of time. While the greater majority of men (69%) had been able to discuss their TRT options, this was not the case for close to a third of participants.
- The provision of information on new TRT products seems to be lacking, with close to half of the participants (48%) not receiving any information for more than a year.
- A very high proportion of men (90%) were bothered by the gynaecomastia associated with KS, with nearly three-quarters (74%) feeling less masculine as a result. The provision of treatment for gynaecomastia seems to be uneven (perhaps a symptom of the NHS postcode lottery). Having to attend a breast unit was generally associated with feelings of embarrassment.
- Men with KS can experience genital size inhibition. In this group of participants, 51% rated themselves as having a slightly smaller or much smaller penis than someone else their own age and build. Three quarters rated themselves as having slightly smaller or much smaller

testicles than someone else their own age and build. There was a certain amount of embarrassment associated with having to have one's genitals examined by a HCP (reported by 30% of participants). Again, the provision of treatment seemed to be uneven; obtaining appointments for appropriate discussions required a certain degree of persistence on the part of some participants.

- Participants were generally satisfied with the emotional support provided by friends and family. However, a third of participants were disappointed with the emotional support provided by HCPs, while a quarter were similarly disappointed in relation to help-line services and on-line forums.
- There is an absence of readily available KS-related information. For example, well over half the participants (63%) did not know where to find information about possible treatment options. The information provided by the KSA was rated very highly, with 64% of participants using it to help them ask questions of their health care team. The existence of the KSA and its promotion by HCPs seems to be somewhat limited.
- The newsletter is far and away the most popular service provided by the KSA. Close second is the KSA website. New services that participants would like to see the KSA offering include advice on identifying/contacting consellers, and Regional Adult Support Groups.

### **Recommendations**

- Increase awareness and understanding of the condition across the medical community, in particular all non-endocrine specialist staff.
- Lobby for the development of guidelines for the treatment of KS, to include such features as regular reviews of medication, provision of information on treatment choice, mechanisms for the provision of information on new TRTs, and provision of information on relevant support groups (such as the KSA).
- Training for healthcare professionals to enable them to better understand and communicate with patients on certain sensitive issues such as size of genitalia and gynaecomastia, sexual issues, and infertility. Attendance at NHS breast clinics to be managed to minimize the potential embarrassment to men.
- Information on sleep management and social skills training may be beneficial for some individuals with KS.

- Psychological support and/or counseling services may be helpful for some individuals to assist with emotional support and the management of the appearance-related issues. HCPs may need some specialist training to enable them to provide such assistance.
- Lobby for GP training to include genetic problems and how to recognise them and appropriately support and manage the care required.
- Lobby to get the NHS website to provide accurate information on the symptoms and impact of KS. Suggest links from the NHS website to relevant support organizations, such as the KSA.
- There are a variety of services offered by the KSA which do not seem to be much used. A more thorough review of actual use of these services may result in the KSA being able to use some of its resources to add some of the new services requested by the participants in this study.