

Development of a Digital Patient Passport to Address the Psychosexual Needs of Patients with Klinefelter Syndrome

INTRODUCTION

- Klinefelter Syndrome (KS) is one of the commonest chromosomal aneuploidies yet lack of awareness within the medical community and subsequent lack of patient resources persists.
- Management is often complex, requiring multi-specialty input including: urology, genetics, endocrinology, reproductive medicine, and psychosexual medicine.
- Patient passports are a tool that can be used to improve continuity of care and enhance patient experience by condensing all relevant information within one document.
- Psychosexual implications of KS include: delayed ejaculation, sub-fertility, erectile dysfunction, low libido and gender dysphoria. These implications can impact patients' mental health and interpersonal relationships.
- We developed a patient passport to better support the psychosexual needs of KS patients.

METHODS

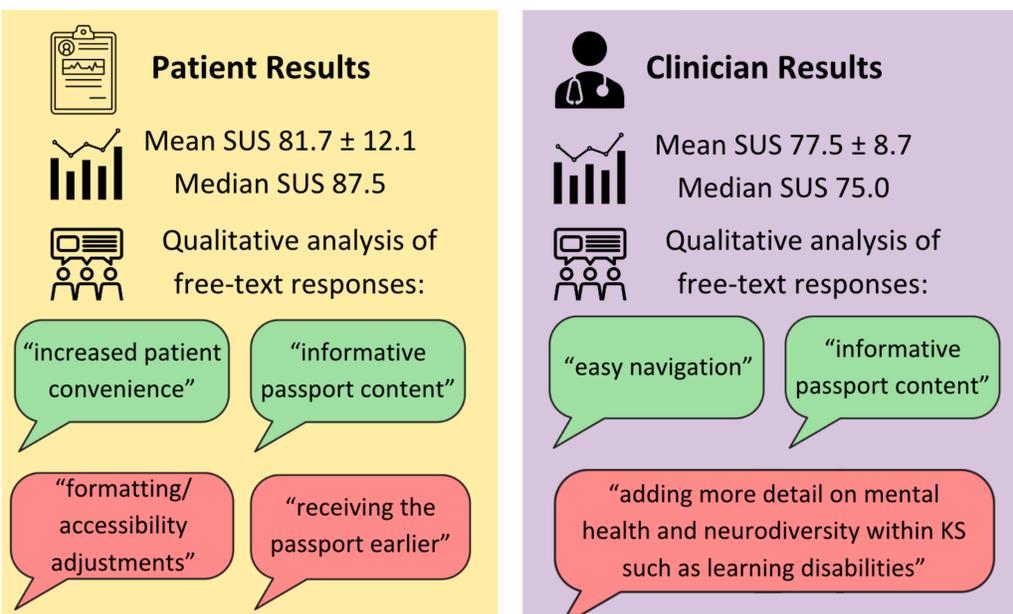
- A fully digital patient passport was developed for patient and clinician education on the psychosexual impact of KS.
- Two plan, do, study, act (PDSA) cycles were performed over four months in a multidisciplinary Klinefelter clinic with psychosexual specialist input.
- Both Patients and Clinicians evaluated the tool via questionnaire completion including the System Usability Scale (SUS) and free-text questions on the positive and negative aspects of the tool. Patients were additionally asked a series of questions about information provided in the KS passport.

System Usability Scale Questions

1. I think I would like to use the KS patient passport frequently
2. I found the KS patient passport unnecessarily complex
3. I thought the KS patient passport was easy to use
4. I think I would need the support of a technical person to be able to use the KS patient passport
5. I found the various functions in the KS patient passport were well integrated
6. I thought there was too much inconsistency in the KS patient passport
7. I would imagine that most would learn how to use the KS patient passport very quickly
8. I found the KS patient passport very awkward to use
9. I felt very confident using the KS patient passport
10. I needed to learn a lot of things before I could get going with this system

RESULTS

PDSA Cycle 1



PDSA Cycle 2

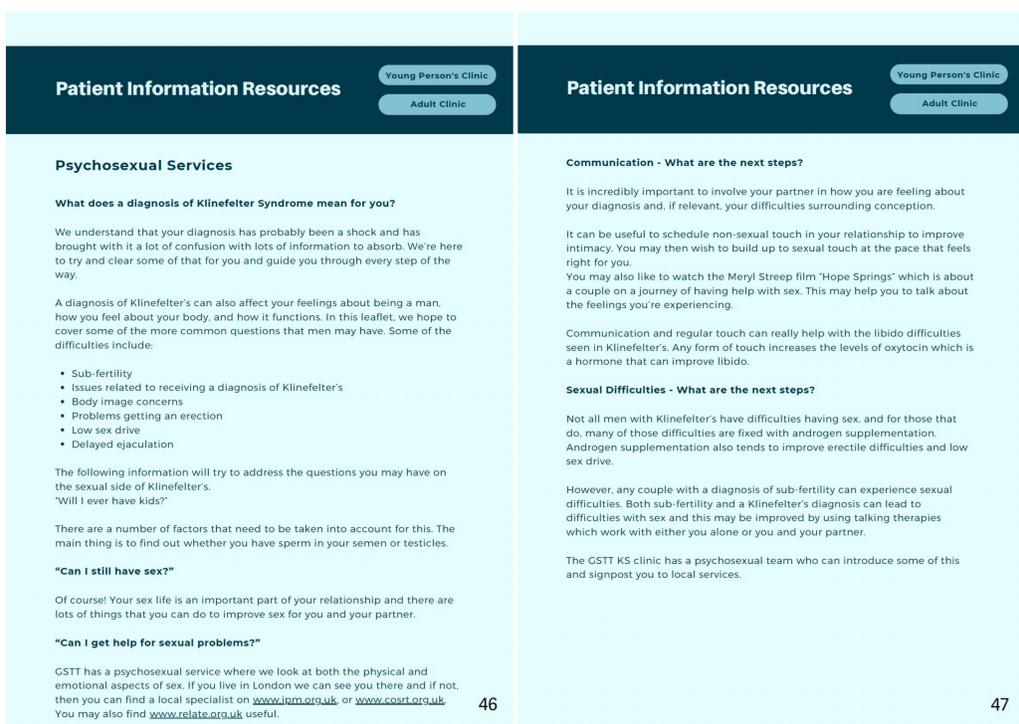
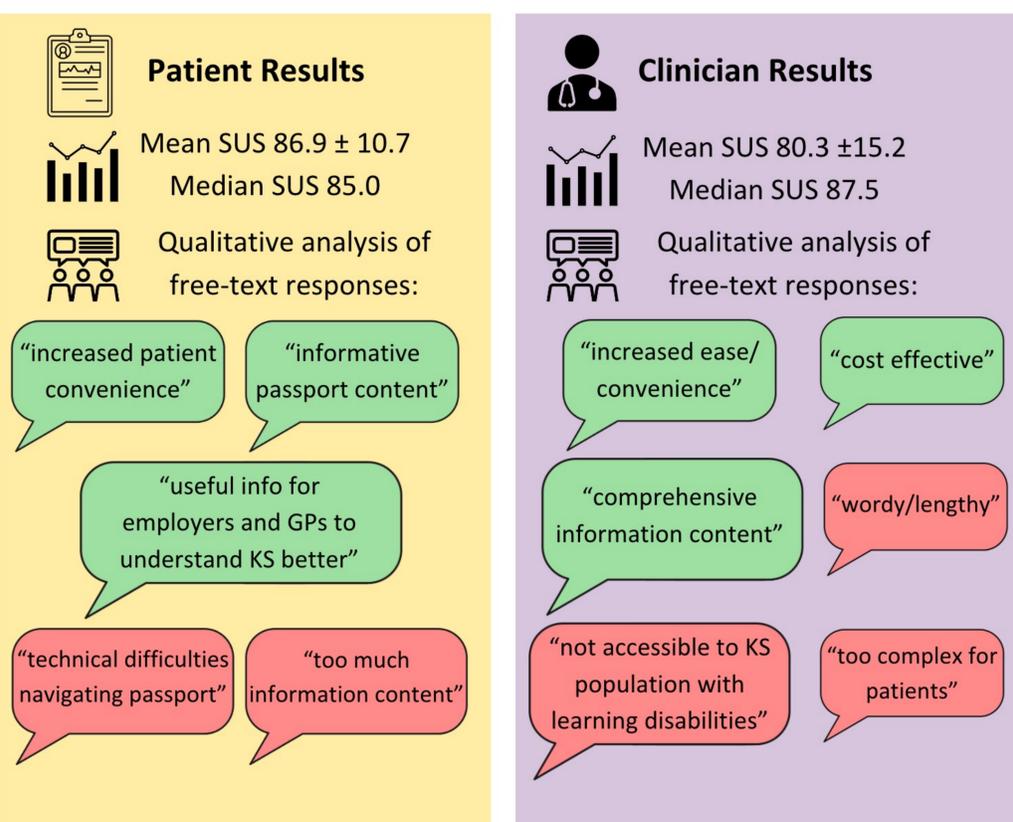


Figure 2 Excerpts from the patient passport outlining psychosexual support for patients with Klinefelter Syndrome

DISCUSSION

- There is demand for the distribution of psychosexual information resources to patients ahead of clinic attendance.
- System usability was perceived as excellent by patients and good by clinicians demonstrating the effectiveness of patient passports as a tool to improve psychosexual support and knowledge in KS.
- It is important to consider the high prevalence of neurodiversity amongst KS patients when designing patient resources to ensure accessibility for all.

CONCLUSIONS

- Psychosexual difficulties are a common, but often neglected aspect of KS management.
- It is imperative that all KS patients receive input from psychosexual specialists as part of their ongoing care and have access to clear and comprehensive information resources for advice and support.
- Work is now in place to develop an app for enhanced usability.

Figure 1 Summary of patient and clinician results