

Patient experience, quality of life and unmet need in UK CML community

Andrea Preston¹, Nick Duncan^{2,3}, Kim Summers¹, David FitzGerald⁴, Nigel Deekes⁴, Georgina O'Neill¹, Orlando Agrippa¹

¹Sanius Health, London, United Kingdom, ²University Hospitals Birmingham NHS Foundation Trust, ³University of Birmingham, ⁴CML Support, United Kingdom

Objective

To capture quality of life (QoL), symptom burden and unmet need in the UK CML community, including acceptability and demand for digital healthcare solutions (including the smartphone application 'My CML').

Conclusions

- Despite significant advances in the management of CML, most patients live with side effects which impact their QoL.
- Capturing PRO data can optimise therapy and drive crucial real-world evidence generation.
- Biometric monitoring is an unmet need in the CML population.

Background

With the introduction of tyrosine kinase inhibitor (TKI) therapy, patients with Chronic Myeloid Leukaemia (CML) have a life expectancy close to that of the general population. Considering the impact of long-term treatment on quality of life (QoL) is critical to improve healthcare quality and optimise outcomes.

Self-reporting of patient reported outcomes (PROs) provides the unique patient perspective and has demonstrated benefits on overall and progression free survival in cancer.

Understanding the unmet need is paramount to improving service-provision, new therapies, and patient outcomes. Smartphone applications, wearable technology and associated digital health technological innovation provide an opportunity for continuous patient monitoring, as well as greater engagement, autonomy, and responsibility for managing health.

In this study we aimed to capture QoL, symptom burden and unmet need of the UK CML community, including acceptability of digital healthcare solutions.

Results II

A total of 64 patients responded, aged 29 to 77 years (median 55- see figure 1). 25% were male (n=16), 71% female (n= 46), 2% (n=1) non-binary and 2% (n=1) preferred not to say.

Current treatment included imatinib, nilotinib, dasatinib, bosutinib, ponatinib, and asciminib, with 35 (54%) in first-line setting and 29 (46%) beyond first-line. 5 patients had achieved a treatment-free remission (treatment discontinued). See figure 3.

59 patients (95%) reported living with side effects (any grade).

The most common side effects were muscle and joint aches/ pains (78%), skin problems (72%), and drowsiness (70%). Common concerns included worrying about future health (81%) and risk of infection (69%).

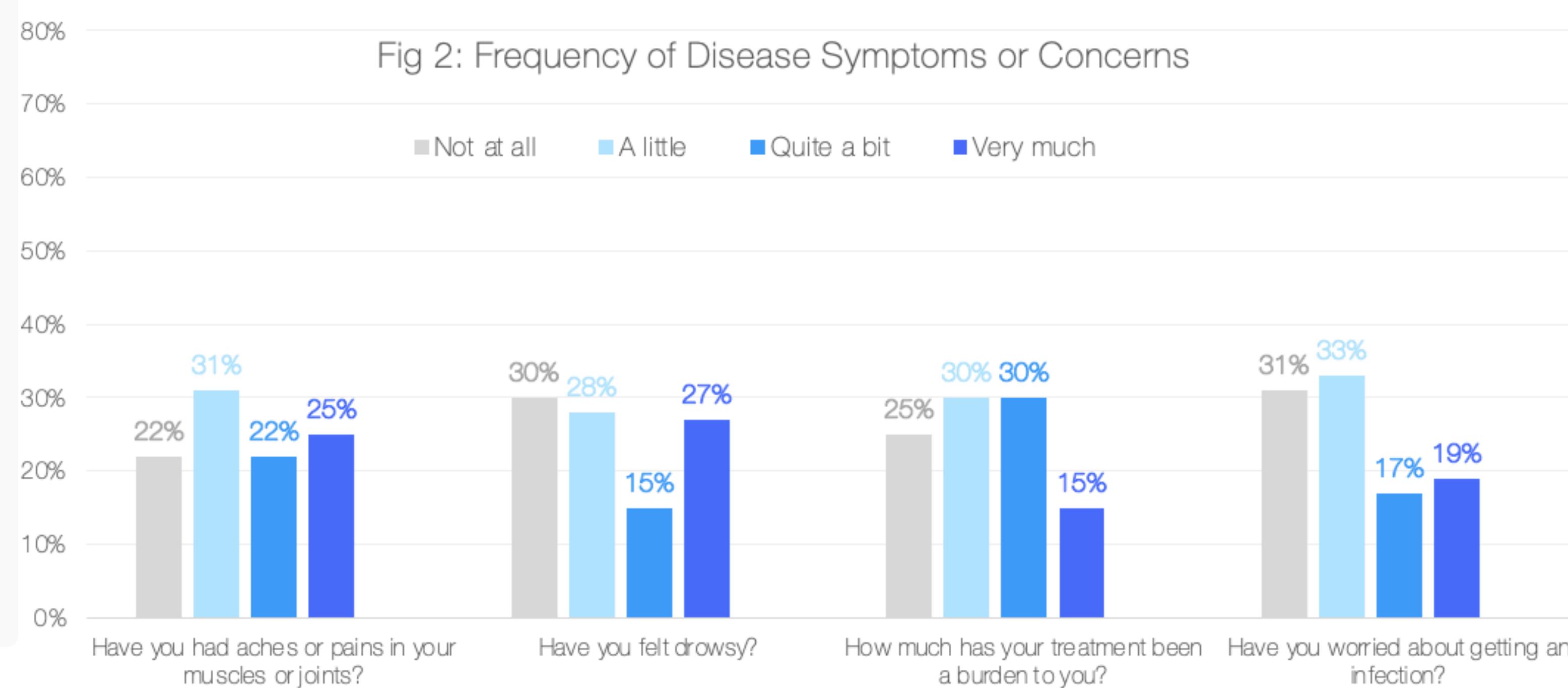
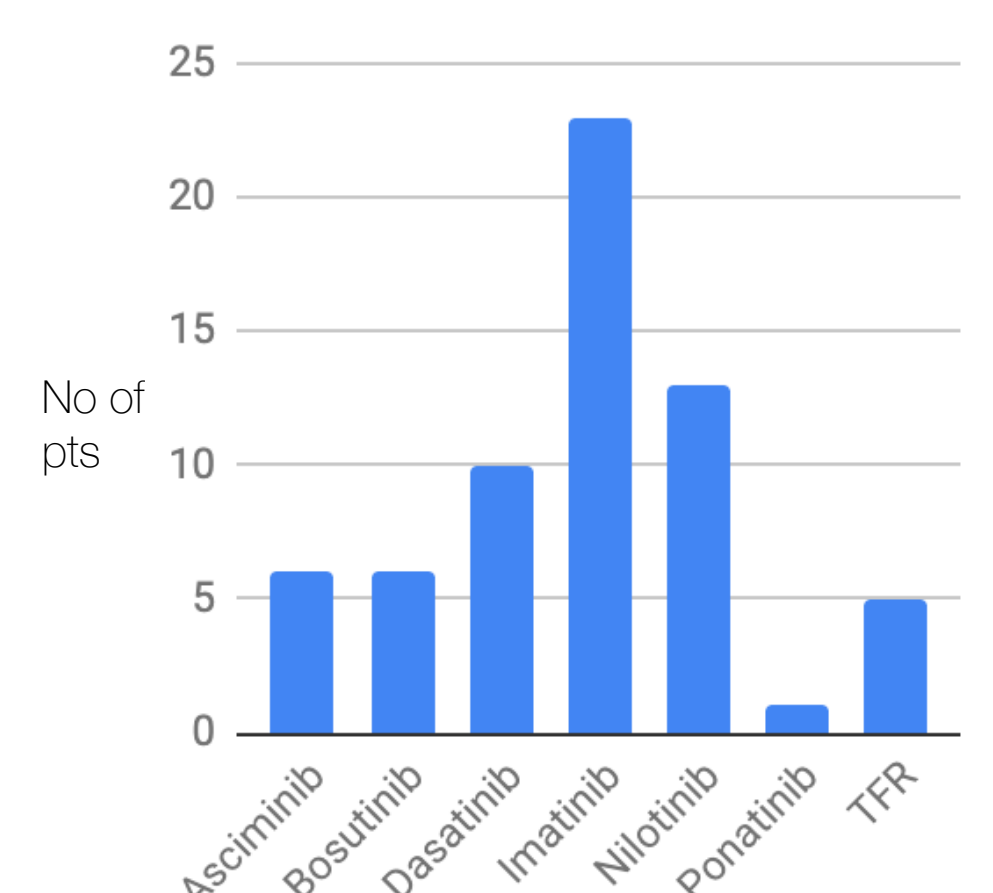


Fig 3: Current treatment regimen



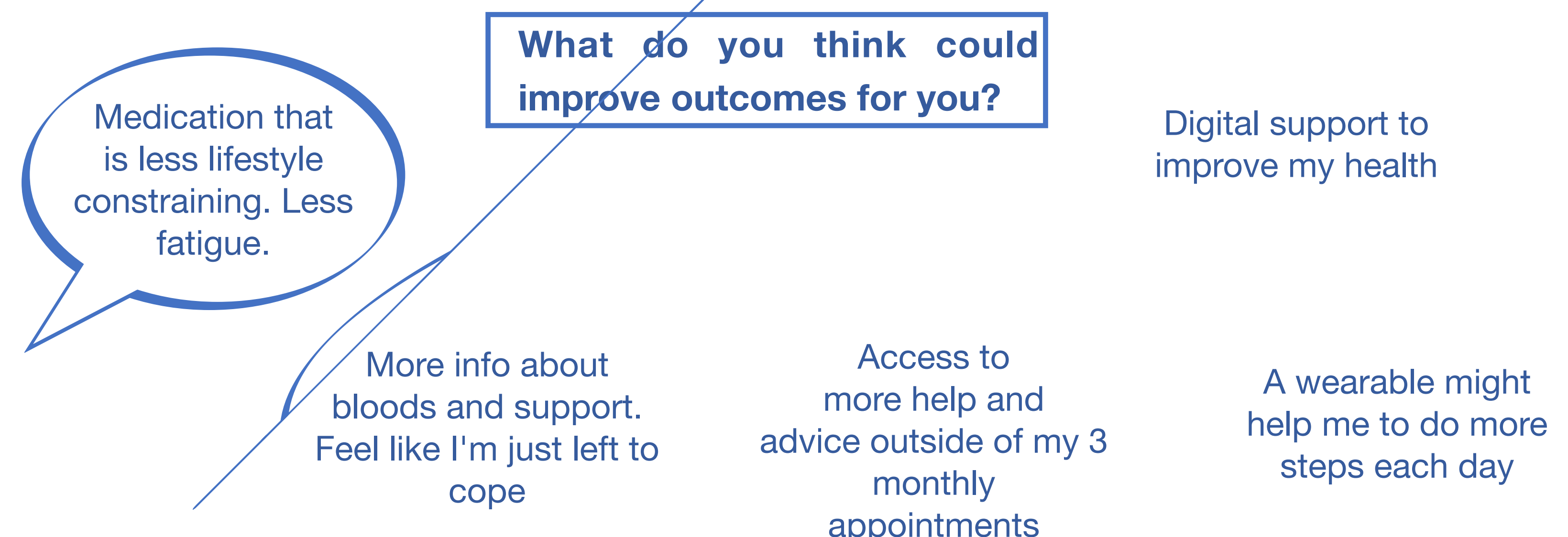
Methods

In partnership with CML patient support groups we created an electronic patient questionnaire. Alongside demographic and treatment parameters, QoL and symptom burden were assessed via the EORTC QLQ-CML24 tool.¹

Uptake and acceptability of the smartphone application 'My CML' was assessed. Patients were asked about unmet needs, challenges and what could improve outcomes.

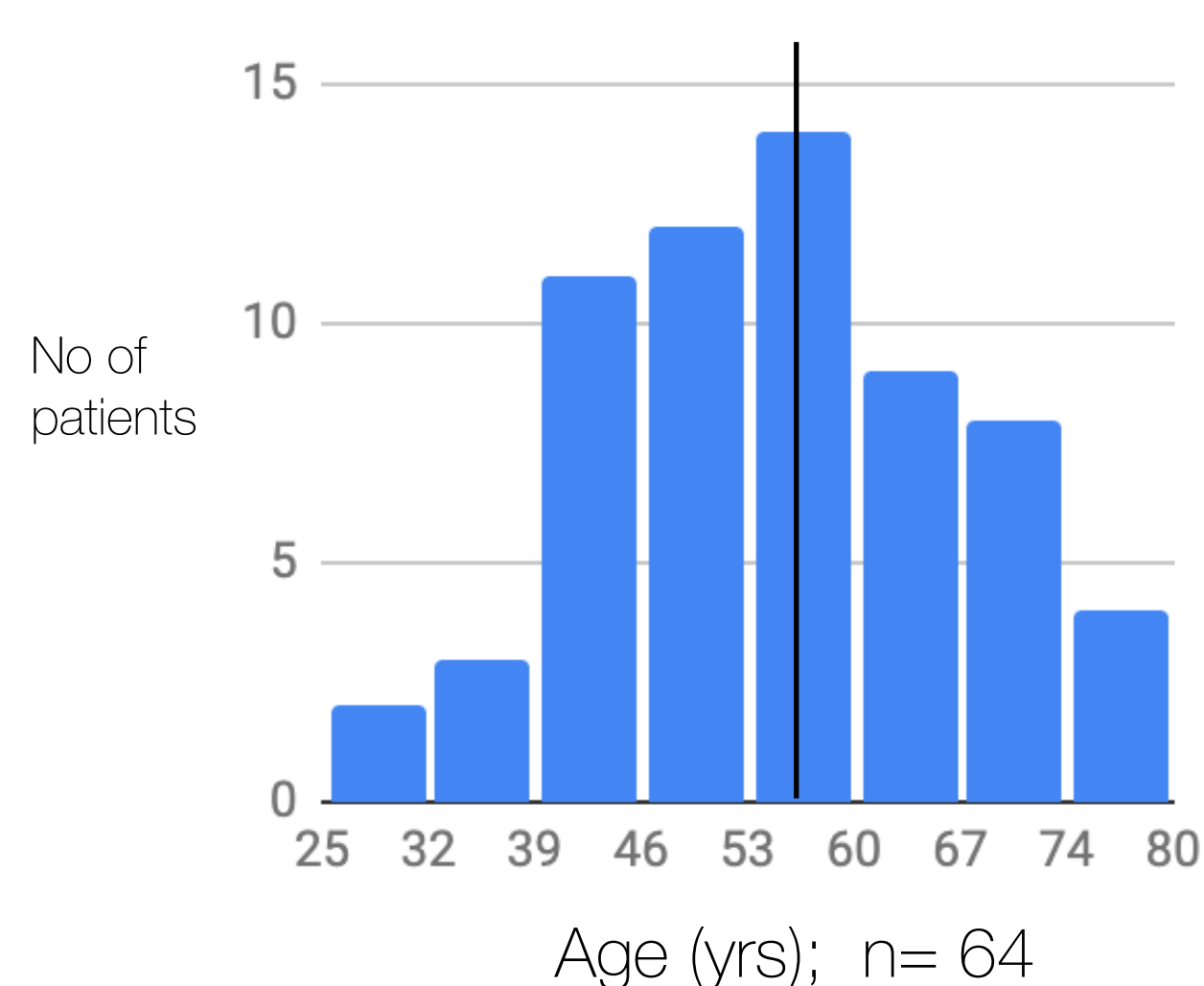
A total of 36 patients (56%) had used the 'My CML' app, with the most helpful features being tracking blood results, recording/ tracking symptoms, and a drug interaction checker.

49 patients (77%) were keen to support their CML management with a wearable device.



Results I- Age distribution

Figure 1



References

1. Fabio Efficace Michele Baccarani, Massimo Breccia et al. International development of an EORTC questionnaire for assessing health-related quality of life in chronic myeloid leukemia patients: the EORTC QLQ-CML24. Qual Life Res 2014 Apr;23(3):825-36

Contact

nigel@acres.co.uk david@fitzg.com nick.duncan@uhb.nhs.uk andrea@saniushealth.com orlando@saniushealth.com