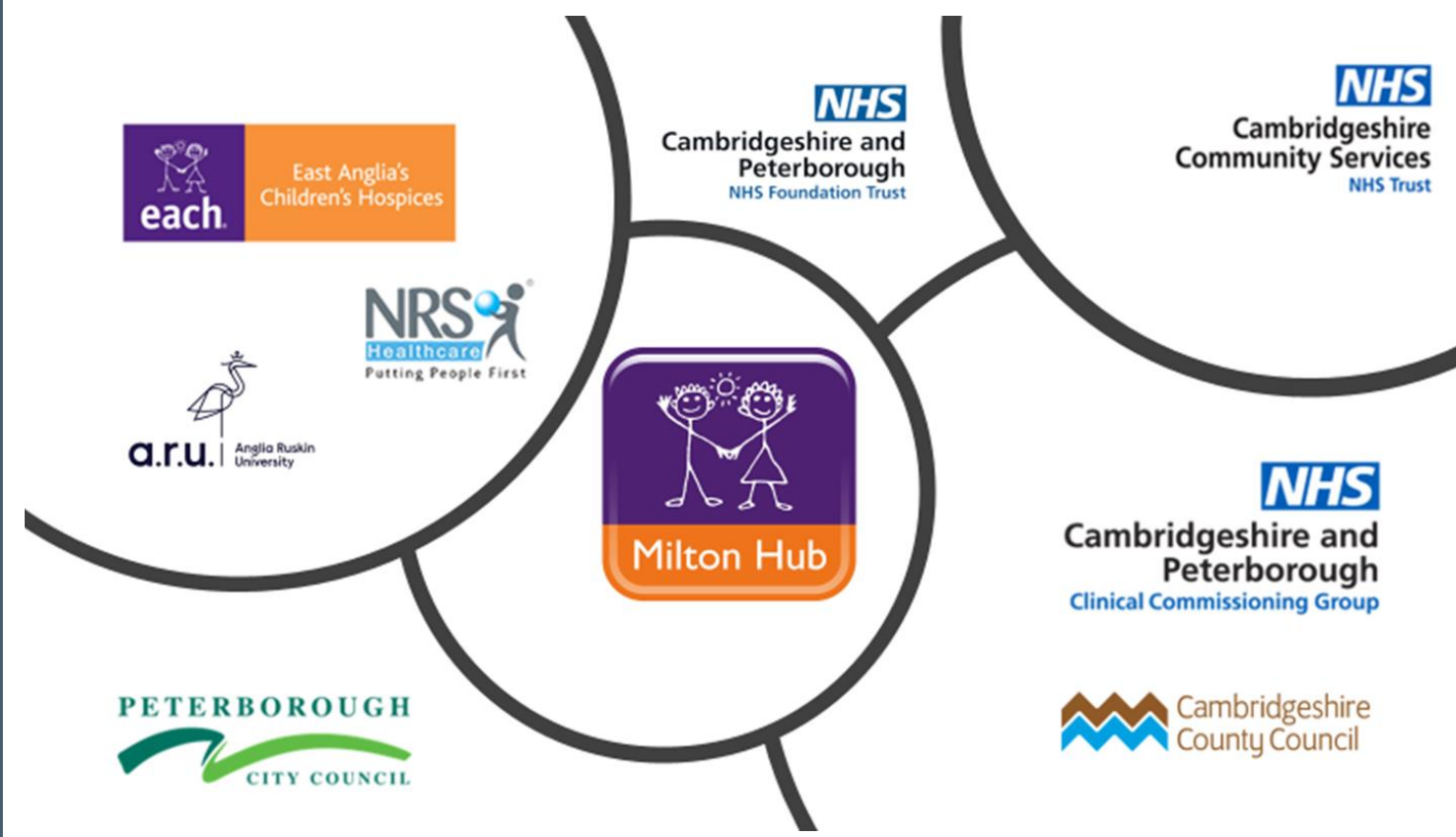




Supporting Parents of Children with Palliative and Complex Health Care Needs in a Time of Crisis: A Health and Social Care System-wide Response

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Introduction

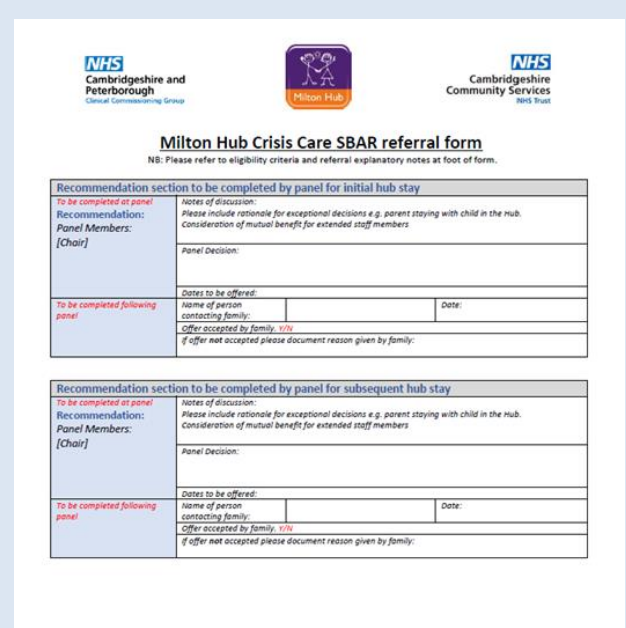
During COVID 19 pandemic children (CYP) with highly complex medical health care needs experienced crisis due to disruption in usual care.

This collaboration project provided crisis led short break care (SBC) using system-wide healthcare skilled staff in-reaching into a children's hospice.

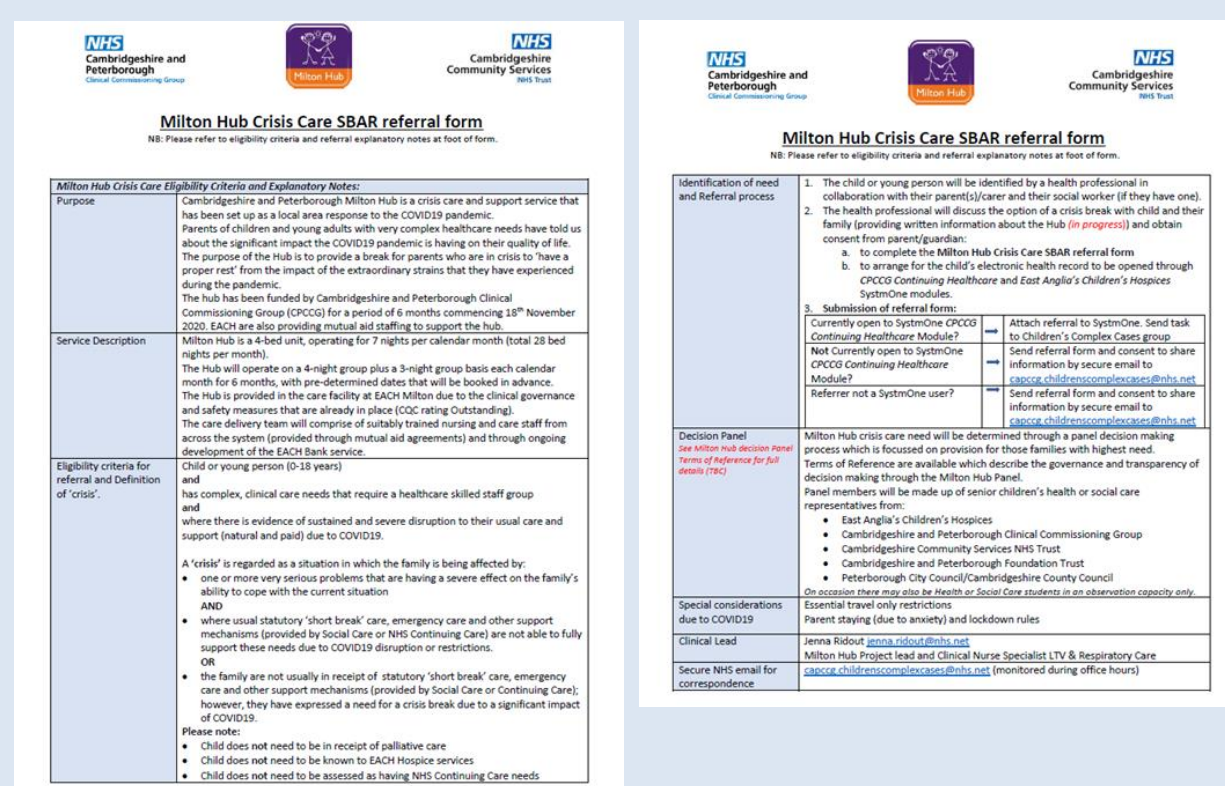


Methods

Eligibility for service: children (0-18 years) with complex needs requiring healthcare skilled staff and evidence of sustained / severe disruption to usual care due to COVID 19.



Crisis defined as: a situation affecting family ability to cope with current situation and, if usual SBC / support mechanisms not able to meet needs.



Governance:

- All healthcare organisations conformed to NHS Information Governance standards.
- Use of shared system of electronic clinical record keeping (SystemOne).
- Referral Panel documents (and any subsequent documentation e.g. where further information or clarification was required / obtained) scanned to the electronic record.
- Care planning processes in advance of stay at the Hub.
- Where any paper care records were used (e.g. Paediatric Early Warning Score chart, Medicines Administration Record, Fluid Chart) these were scanned to the electronic record at the end of the SBC Hub stay.

Evaluation: Survey used to capture parent expectations on child admission to the Hub and repeated on discharge. Anonymous survey to hear staff feedback.

Findings: Child and Family Experiences

Fifty CYP were considered for crisis care:

Nine CYP were declined by the Referral Panel as not meeting eligibility

Eight CYP meeting criteria did not stay (deferred / died / unknown reason)

From 1.11.2020 to 31.10.2021:

There was delivery of nights (n=279) for crisis care were delivered to CYP (n=33)

Multiple stays received by CYP (n=22).

Quantitative feedback on defined experiences noted agreement in admission and discharge responses: 59/65 achieved proper rest

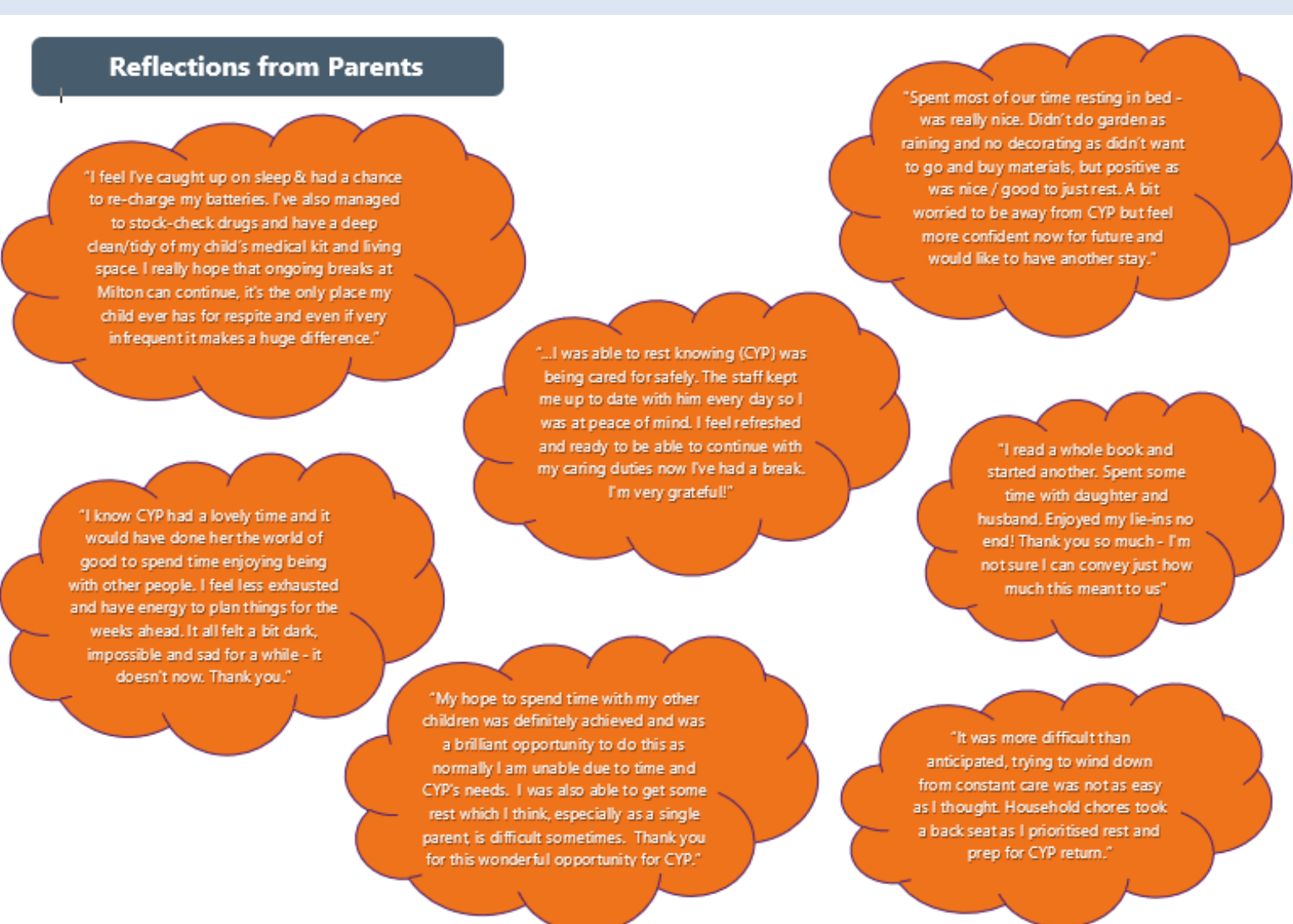
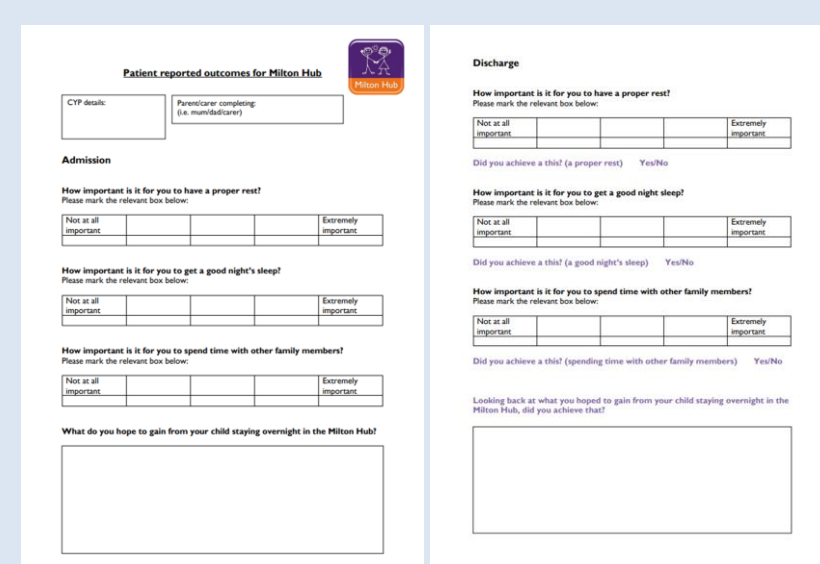
57/65 achieved good night's sleep

55/58 achieved quality time with family members.

Qualitative analysis of parents hoped for achievements

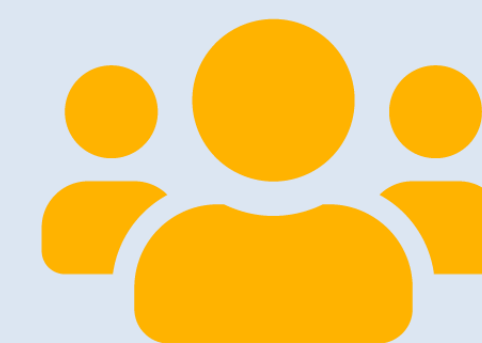
identified 5 themes: increasing trust in professionals;

prioritising 'me' time; performing household tasks; break from alarms; socialisation for CYP.



Findings: Workforce

Staff (n=37) felt useful and valued and felt able to make a difference especially during the pandemic. There was an increased sense of developing team working and support, as well as practical individual skill development.

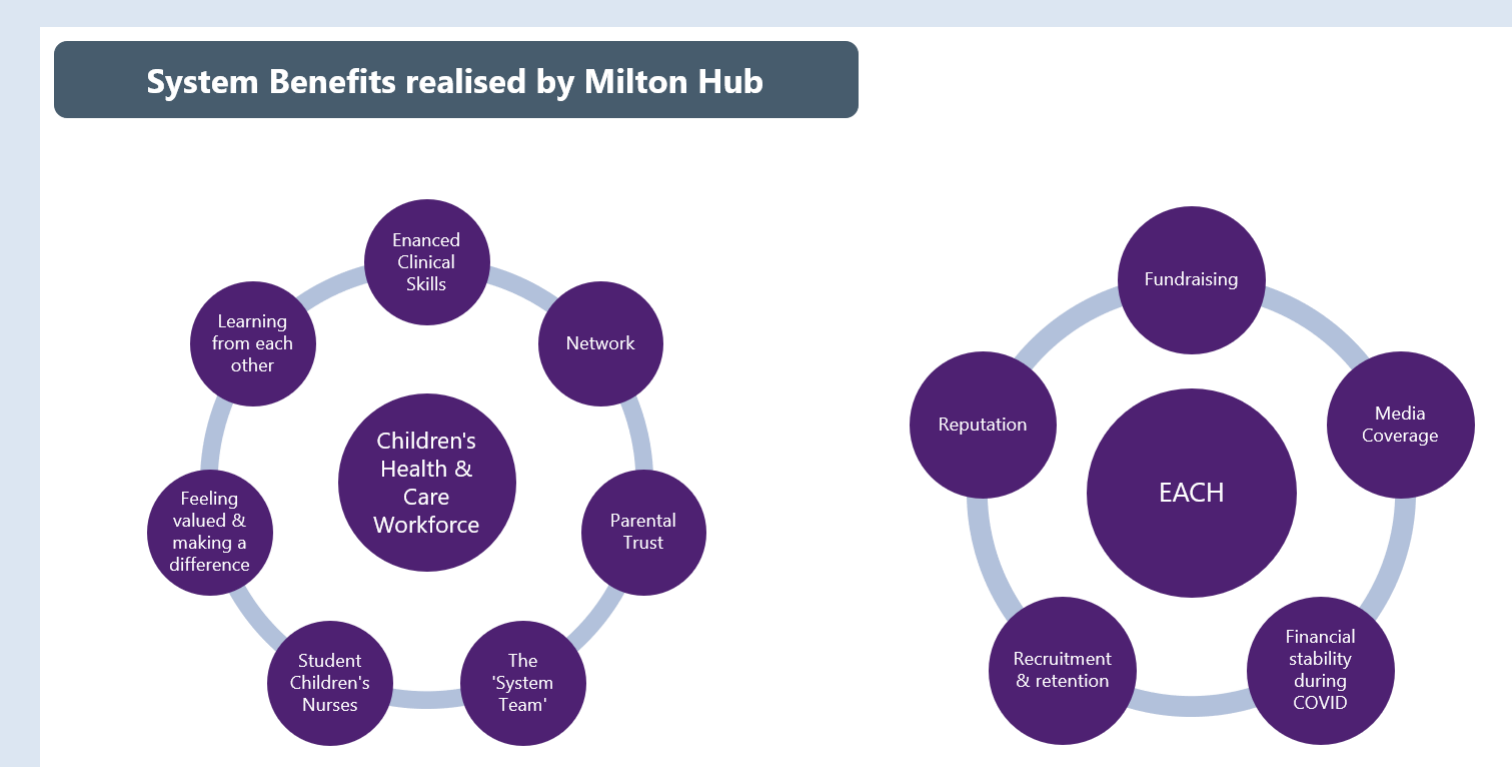


Learning and System Benefits

Vital support was given at a reliable location at times of extreme stress / anxiety to hard to reach families, with opportunity to develop trust in professionals.

Service provision challenges:

- Maintaining delivery of hospice 'usual business' i.e. end of life care provision
- Impact on choice of place of care for others needing end of life care
- Communicating and managing decisions when families were well known to the system who didn't meet eligibility
- Ensuring external professionals understood referral criteria
- Staff absence (sickness) was sometimes hard to cover
- Satisfactory induction to hospice processes for system wide staff
- Care planning in advance for safe care
- Distance and travel time for some families to get to the Hub
- Providing clarity about holistic services e.g. inclusion of play therapy, art, music and fun!



Conclusion

There were mutual benefits gained from system team working. Including:

Sharing information; joint assessment and care planning; holistic view of support for families either independently or as a planned intervention; maintaining clinical safety and observation at a time when many children were having less contact with schools and health care professionals.

Positivity was expressed by professionals at being able to offer a service to families in desperation. A grateful parent summarised what it meant to them:

"...A break; my sanity; just to be 'me' for a short time; for my child to have a break..."

References

NHS England » Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026

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