We developed virtual parent support groups and psychological health screening for adolescent patients in clinics. We organised a 'Tree of Life' (ToL) patient empowerment workshop. The parent support groups were well attended. Plans are in place to continue ToL workshops and support groups on a regular basis.

Future work: A rapid improvement workshop is being planned to engage a wider multi-disciplinary team to engender a culture of empathy in line with our trust values. Further input from workshop is expected to identify and implement sustainable goals. We plan to undertake a repeat PREM survey following the end of this CQI project to understand the impact and the implemented improvements.

References

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S129 IMPLEMENTATION OF HYDROXYUREA THERAPY FOR SICKLE CELL DISEASE ON A LARGE SCALE IN GHANA

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Background: Hydroxyurea (hydroxycarbamide), has had a most profound and broad ameliorating impact on the clinical course of sickle cell disease (SCD.) Although relatively inexpensive, hydroxyurea (HU) has not been widely available to the large majority of people with SCD who happen to live in low-income countries.

In 2018, in preparation for the establishment in 2019 of a broad-based Public Private Partnership (PPP) in SCD involving the Ghana government and Novartis, a group of parents Novartis to provide HU at a lower price for use in Ghana. Novartis produced 500mg capsule of HU and submitted it to Ghana Food and Drugs Authority registered the medicine for the specific indication of SCD in October 2018.

The Sickle Cell Foundation of Ghana (SCFG), a partner in the PPP was tasked to develop the Ghana-Novartis Hydroxyurea-for-SCD Program ("Ahodwo [pr. A-ho-jo] Program", meaning, "Program for Relief".). The program was conceived as an implementation study to determine whether treatment with HU, specifically registered in Ghana for SCD, can be safely implemented and monitored on a large scale through an organized treatment program within the public health service in Ghana.

Methods:

1. Treatment Protocol: A team of Ghanaian SCD experts developed an HU-for-SCD dose-escalating, maximum tolerated dose (MTD) Ahodwo Protocol adapted for Ghana. A unique feature of the protocol is the selection of Hb level of 10g/dL as the primary goal of HU therapy with of a Therapeutic Dose (TD) defined as, "the dose at which Hb 10 g/dL or higher is achieved and maintained over a period of 12 weeks".
2. Treatment Teams: Established SCD Treatment Centres (SCD TC) were surveyed for patient numbers, age groups, Hb Phenotypes, and available laboratory services. Doctor-nurse-pharmacist teams were recruited from 11 TC located in four Regions of Ghana in Phase 1 of the Program for training. A year later, 9 smaller SCD TC were added to the program, in Phase 2, extending it to two additional Regions.
3. Ahodwo Program App: In order to register and guide healthcare professionals (HCP) on the protocol, register all subjects, assist with dosing calculations, and monitor the entire program, a secure, smartphone-based mobile application, Ahodwo Program App, was developed, tested, and deployed to all HCP in the program. Recording toxicity and reporting all expected/unexpected adverse events were mandated and reportable through the App.
4. Steering Committee (ST): A ST comprising clinician leaders of the TC was established; the ST held bi-weekly online review meetings for the first year and monthly thereafter. All HCP teams met every quarter.

Results: Table, below, lists the number and characteristics of subjects registered in the Ahodwo Program.

Data Elements	Phase 1	Phase 2	TOTAL
Number of SCD Treatment Centers (TC)	11	9	20
Number of subjects on HU	3,357	291	3,648
Average, No. of Subjects at TC	305	32	182
Median, No. of Subjects at TC	256	26	88
Range, No. of Subjects at TC	(46, 694)	(7, 94)	(7, 694)
Female, No. (%)			1,728 (47.4%)
Male, No. (%)			1,920 (52.6%)
Age < 10yr, No. (%)			1,561 (42.8%)
Age 10-18yr, No. (%)			1,295 (35.5%)
Age > 18yr, No. (%)			792 (21.7%)
Presumed SCD-SS or S/beta-zero, No. (%)			3,526 (96.7%)
SCD-SC, No. (%)			122 (3.3%)

On June 19th, 2021, World Sickle Cell Day, the government of Ghana announced the provision of HU for people with SCD through the National Health Insurance Scheme. Following preparatory meetings to establish the required regulatory standards, implementation of the national program is expect

Conclusion: Our experience supports the tenet that hydroxyurea can be safely and effectively administered at population scale in a low-income country. Long-term sustainability in this setting is likely to be dependent on a government-supported access programme. The pioneering efforts of the government of Ghana to provide HU to its citizens with SCD are laudable and serve as a model to guide similar efforts in other low-income countries.

S130 PROCESSING SPEED DECLINES OVER TIME IN 4--25-YEAR-OLDS WITH SICKLE CELL DISEASE

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Background: Alongside physiological symptoms, young people with sickle cell disease (SCD) may also experience cognitive difficulties, including poorer processing speed. Processing speed develops rapidly from birth to around mid-childhood, with steady improvements thereafter into a person's mid-twenties (Anderson, 2002). Nonetheless, little is known about the dynamic developmental trajectory of processing speed for young people with SCD.

Aims: This study, we aimed to investigate if the change in processing speed index (PSI) over time is significantly different between younger participants (aged under 8.99 years at first assessment) and older participants (over 9 years at first assessment) with SCD.

Methods: One hundred and five participants with SCD aged 4 – 18 (N < 8.99 = 47; N > 9 = 58) at recruitment consented to follow-up IQ assessments (WPPSI-R, WISC-III, WAIS-R or WAIS-III) and MRI scans

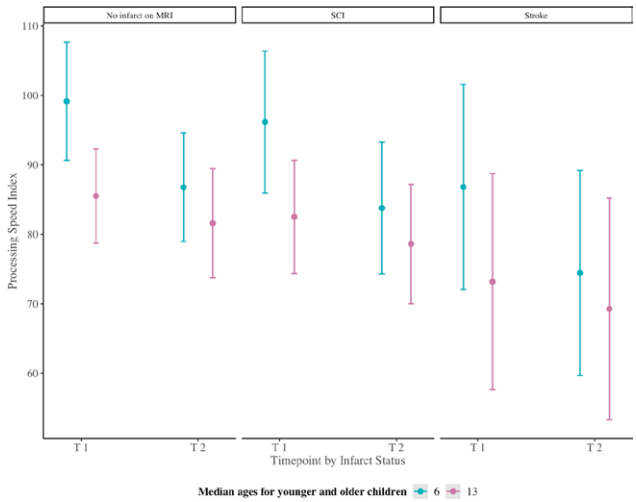

Figure 1. Processing speed index at timepoint 1 and timepoint 2 for participants under 9 (median age 6 years) and over 9 (median age 13 years) years by cerebral infarct status