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Identifying Barriers to Access to Treatment with Hydroxyurea for Patients with Sickle Cell Disease – A Qualitative Analysis of the Supply Chain in Ghana

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KEY FINDINGS & CONCLUSIONS

- Key findings:**
 - Lack of **accurate data** about the numbers of patients with SCD in Ghana
 - High **financial barrier** to access treatment with hydroxyurea
 - Lacking **decentralization** of treatment with hydroxyurea
 - Compromised **availability** of hydroxyurea
- Conclusion/next steps:**
 - Promote **universal newborn screening** programs to ensure nationwide aggregation of data
 - Ensure reimbursement of hydroxyurea through **National Health Insurance Scheme**
 - Increase accessibility to treatment with hydroxyurea for patients in rural areas (**decentralization of care**)
 - Promote **training** of personnel and improve **storage conditions** at lower-level facilities
 - Invest in **digitalization** as a common denominator for the challenges mentioned

INTRODUCTION

- Hydroxyurea is an approved disease modifying therapy for patients with sickle cell disease (SCD), which reduces complications associated with SCD and therefore increases quality of life while prolonging life expectancy. Access to comprehensive disease management varies greatly between high- and low-resource countries (Kato et al, 2018, p.11). This study therefore aims to examine how patients with SCD in Ghana access hydroxyurea treatment. Since a country's supply chain management plays a crucial role in enabling access to pharmaceutical products, this paper also addresses two sub-questions:
 - What is the status-quo of the supply chain of hydroxyurea in Ghana?
 - What barriers can be identified that hinder SCD patients from accessing treatment with hydroxyurea in Ghana?

METHODS

- Data collection:** We conducted qualitative in-depth semi-structured interviews with 10 key stakeholders involved in the supply chain of health commodities, including but not restricted to hydroxyurea. The section below gives an overview of the interviewees that were selected to collect the qualitative data. The questions asked in the expert interviews were supported by a preparatory interview guide containing of semi-structured questions. The interview guide was reviewed by the study team ahead of the virtual interviews.
- Data analysis:** The responses received were examined based on a qualitative content analysis. The study thereby focused on the transcripts of the qualitative expert interviews. By comparing the answers of the interviewed experts, the content analysis provides insight into connections, processes, and causal dependencies
- Data presentation:** The results of the content analysis are presented in a process map to depict a whole process and to better understand the hardships patients face to access the care they need. Additionally, the data collected are shown in a causal loop diagram that illustrates how factors within a system influence each other and reveals a system's underlying structures. Finally, the main barriers that were identified based on the results of the content analysis, the process map and the causal loop diagram are presented.

Selection of interviewees

- The interviewees were selected either based on their expertise on and involvement in the supply chain of health commodities (including but not restricted to hydroxyurea) in Ghana or based on their involvement in treating patients with SCD in Ghana with hydroxyurea. The scope of expertise of the interviewees was not limited to the supply chain of hydroxyurea only to ensure a holistic overview of the supply chain of health commodities.
- In total, 10 interviews with representatives of all entities that were identified to play a major role in the supply chain of health commodities (including hydroxyurea) in Ghana were conducted.

Table 1 List of interview partners

Entity	Interviewee Function
Novartis Ghana	Cluster Franchise Head Oncology and Immunology, Hepatology, Dermatology (IHD)
Addpharma Ghana Limited	Managing Director
WHO Regional Office in Ghana	National Professional Officer Essential Drugs and Medicines
Agogo Presbyterian Hospital	General Pediatrician in Hematology and Oncology
Eastern Regional Medical Store	Store Manager
Ministry of Health Ghana	Chief Program Officer Pharmacy
Ernest Chemists Limited Ghana	Brand Manager
Sickle Cell Foundation Ghana	Procurement Officer
Komfo Anokye Teaching Hospital	Senior Specialist Pharmacist in Oncology and Hematology
Ghana Health Services	Director for Supplies, Stores, and Drug Management Division

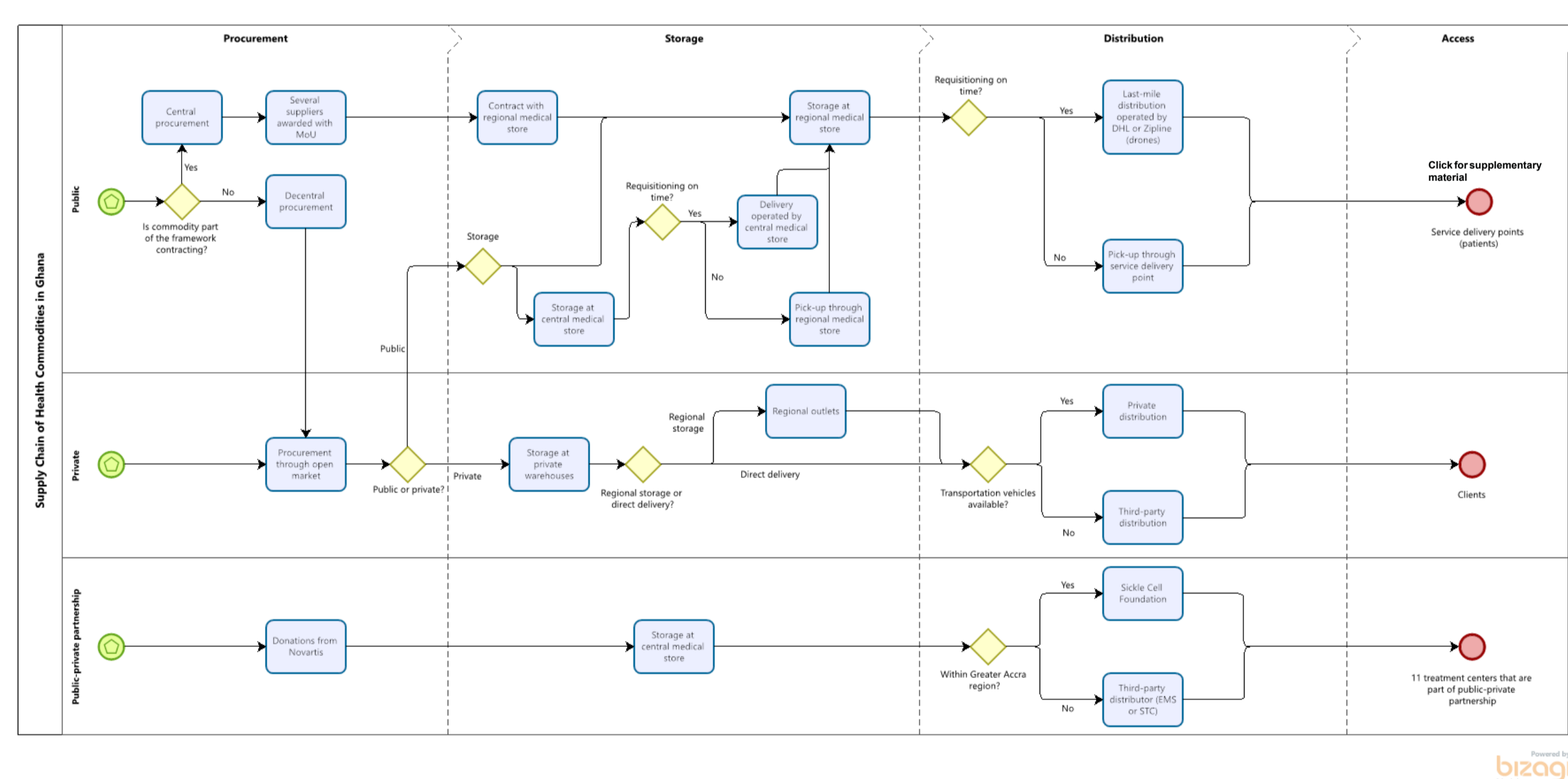
RESULTS

- The results are divided into the following sections:
 - Process Map:** visually represents the data collected through the qualitative content analysis and thereby shows how the supply chain of health commodities works in Ghana.
 - Causal Loop Diagram:** shows the different factors that influence each other.
 - Main barriers identified:** summarizes the main barriers that patients with SCD face to access treatment with hydroxyurea in Ghana.

Process Map

- This section visually summarizes the results from the content analysis in a process map. The detailed information of the content analysis is thereby broken down into the most important parts of the supply chain (i.e., procurement, storage, distribution, and access).
- The process map shows the processes for the public and private channel, as well as within the public-private partnership. The process map represents the current status quo of the supply chain of health commodities in Ghana, including but not restricted to hydroxyurea.

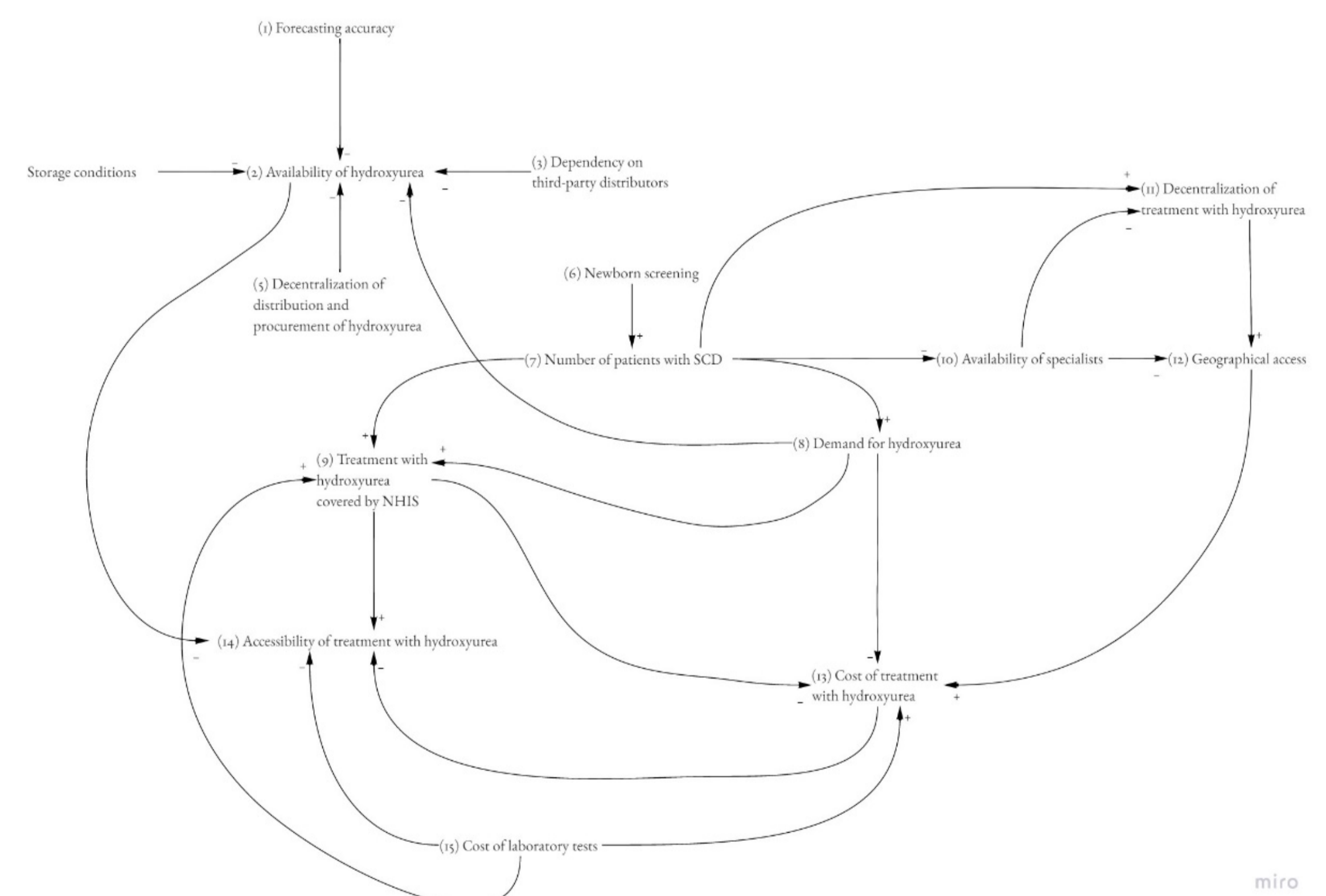
Figure 1 Process Map of Supply Chain of Health Commodities in Ghana (own representation)



Causal Loop Diagram

- The Causal Loop Diagram shows factors that influence each other in regard to the accessibility of hydroxyurea treatment for patients with SCD in Ghana (see figure 2 on the right side).
- Each text component represents a factor, and the arrow shows the direction of influence the factor has on another factor. A factor either has a positive (+) or negative (-) influence on another factor.

Figure 2 Causal Loop Diagram (own representation)



Main barriers identified

- This section summarizes the main barriers that were identified for patients with SCD to access treatment with hydroxyurea and presents possible next steps to overcome these barriers.
 - Lack of accurate data on the number of patients with SCD in Ghana**
 - No data aggregation at national level
 - Statistics on the number of patients with SCD and the number of patients treated with hydroxyurea would allow Ghana an accurate overview and support health policy decision-making
 - No universal newborn screening in Ghana
 - Point-of-care testing tools could advance newborn screening programs in Ghana: Joint efforts, including government institutions (e.g., the Ministry of Health and Ghana Health Service), health facilities at all levels, NGOs, and foundations (e.g., the Sickle Cell Foundation), as well as communities, could lead to great improvements of implementing a universal new-born screening program.
 - High financial barrier to access treatment with hydroxyurea**
 - Many patients with SCD in Ghana are unable to afford treatment with hydroxyurea
 - Regular laboratory tests increase financial burden of accessing treatment with hydroxyurea
 - Incorporating treatment with hydroxyurea (the capsule as well as the accompanying laboratory tests) into the National Health Insurance Scheme (NHIS) would bring great relief to all patients with SCD in Ghana
 - Lack of decentralization of treatment with hydroxyurea**
 - Challenges of geographical access (high transportation costs and long travel distances) leave many patients located in rural areas unable to access treatment with hydroxyurea
 - A decentralization of hydroxyurea treatment to more rural areas is greatly needed to increase the accessibility of treatment with hydroxyurea
 - Decentralization requires more specialists in rural areas
 - With the overall shortage of specialists to administer hydroxyurea, such a decentralization would call for changes in policy: One option would be to allow mid-level practitioners (e.g., medical officers or residents) specializing in hydroxyurea treatment to administer such treatment in rural areas while having remote supervision from experts located in urban areas.
 - Compromised availability of hydroxyurea**
 - Inaccurate forecasting especially at lower-level facilities threatens availability of hydroxyurea
 - To promote training of those in charge of forecasting would increase forecasting accuracy and therefore prevent stockouts or expiries of hydroxyurea
 - High decentralization of procurement and distribution of hydroxyurea with many actors involved
 - Achieving independence from third-party distributors in making hydroxyurea available for patients with SCD would be an important step

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