

PILOT REPORT



**Enhancing Diabetes Mellitus Outcomes
Through Creating a Community of Care
in Rural Pakistan**

[Working Draft]

Partners:





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Executive Summary

Diabetes is a 'silent killer' that continues to be a growing epidemic across many developing countries throughout the world. Early stage diabetes can be ameliorated with a combination of lifestyle changes involving diet and exercise, and taking prescribed medication regularly. Unfortunately in many underprivileged regions in many developing countries, there is both widespread lack of awareness about diabetes and poor access to quality medical facilities. Here 'access' means both financial affordability and geographical distance. Since diabetes often goes undetected until it reaches late stage, the disease continues to claim thousands of lives on an annual basis and physically and financially cripple many thousands more. Given the many challenges that governments of developing countries face, it is unlikely that these governments will be able to implement in a timely manner effective, comprehensive and inclusive policies to tackle this epidemic. This is why it is important to consider community-based solutions, where people and organisations come together to pool in the resources to tackle this problem.

Glucose Trail, with its partners Saving 9 and Mera Maan, have conducted a 12 month pilot study in rural Islamabad in Pakistan. This report documents the findings of this pilot, which combined community mobilisation with telemedicine to provide medical care to dozens of early stage diabetes patients. The findings indicate that the pilot group of patients on the whole improved in their medical outcomes as measured by HBA1C's and glucose levels, whereas those of the control group on the whole deteriorated. This shows promise that the GT community of care model can be of benefit to patients with difficult access to medical services.

This intervention model was refined and tweaked as the pilot was conducted and the challenges and opportunities of the local context presented themselves. This indicates that there is merit in now conducting a larger scale pilot, with lesson learned from this initial pilot incorporated from the outset. Other organisations and individuals are encouraged to conduct their own interventions on the basis of the findings of this report. The next step for Glucose Trail will be to conduct a larger and longer pilot in Pakistan that incorporates the valuable insights gained, and then to eventually work in partnership with stakeholders to scale this life saving and changing intervention across Pakistan and then other deserving parts of the world.

Rationale

Overview of the Diabetes Epidemic in Pakistan

Diabetes is a huge problem globally. The cost of diabetes care is phenomenal and there is a significant economic toll in money spent, productive lives compromised, and health care resources consumed in caring for this chronic disease. The numbers are staggering. 422 million people had diabetes in 2014, and the numbers are increasing every year (WHO, 2019). Using Pakistan as an example (SA et al., 2016), the incidence of diabetes is increasing by 170% in developing countries and estimated to affect 14.5 million in Pakistan by 2025. 77% of people with diabetes will live in low/middle income countries. This threatens their most valuable asset; its young population. 35.7 % of the population is between 25-54 years old. What is alarming is that in Pakistan, 48% of deaths due to diabetes occur in people < 60 years old. This threatens bread winners, mothers, and homemakers. Type 2 diabetes is familial, and a positive family history increases the risk of diabetes by 3-fold. This risk is increased by 7-fold with positive family history and being over 30 years old. This is further made worrisome by the fact that Pakistan's population is growing rapidly. According to the 2017 Census (Pakistan Bureau of Statistics, 2019) Islamabad Capital Territory has 2,006,572 growing at 4.91% per annum; Neighbouring State Punjab has 110,012,442 growing at 2.13% per annum; and neighbouring province Khyber-Pakhtunkhwa has 30,523,371 growing at 2.89% per annum.

The example of the diabetes epidemic in Pakistan above is repeated in neighbouring India, Bangladesh, Sri Lanka other countries in South Asia and Africa. Below are some of the main issues in managing diabetes in low income countries:

1. **Crippling Costs:** Complication rates are higher in low income countries (Dagenais et al., 2016). The disease is diagnosed later, treated randomly and patients present when they need emergency care. At this point, irreversible complications have often set in. Diabetics with severe complications become an enormous economic burden with the loss of individual productivity + cost of expensive health care. In developing countries, people may spend 25-34 % of income on diabetes care. For a family living with a low income, education and nutrition are the critical tradeoffs to cover the cost of health care for a medically complex irreversible health issue.
2. **Focus on Last Stage Intervention Rather than Prevention:** Budget for health care would be better utilised by shifting care from treating critically ill morbid patients with irreversible complications to preserve the health of productive individuals with early intervention (Moucheraud et al., 2019). Treating diabetes early is a lot easier, is relatively inexpensive and motivating through positive outcomes. Treating diabetes late, once complications have set in requires tertiary care facilities, is very expensive, desperate and depressing and often prolongs irreversible misery.

3. **Poor Capacity and Will to Diagnose Early Stage Diabetes:** Diabetes is a silent killer and does not bring people to the hospital in its early stages (Campbell, 2001). Emergencies bring people to the hospital, such as impaired vision, life threatening limb infections, heart failure or advanced kidney disease. At this point it is too late to preserve health, instead it is a lifelong battle to cope with chronic disease. People are unaware of their disease until symptoms present themselves, and often do not take concern about the disease until the symptoms become active. At this stage the patient has spent years with high glucose levels and frequently have developed irreversible complications. A real diabetes care solution needs to be accessible to those most at risk, needs to diagnose the disease early, to provide consistent, affordable, effective care to preserve health and prevent complications (Campbell, 2001).

4. **Medical-Industrial Complex:** Expensive pharmaceuticals and diagnostic testing developed in high income countries are being imported to low income countries without context and being applied sporadically to low income populations, fuelling a hospital-based industry (Moucheraud et al., 2019). This approach is not reducing diabetes complications and preserving health but imposes a crippling expense to its most vulnerable populations. A long history of such problematic interventions in Pakistan has led to a general mistrust by rural communities of 'outsiders' coming in and having them take part in medical behaviour change interventions. Furthermore there is little oversight on quality medical care, or evidence based best practices. Medical care is primarily geared to symptom alleviation rather than data driven treatment goals. Pharmacies carry both cheaper local and international meters, insulin and medications. Most of these are private. Pharmaceutical favours are largely unregulated and can influence physician practices. At a public level many towns have a health care clinic that is government funded, however mostly understaffed, with poor resources and provides little to no diabetes management.

5. **Socioeconomic Social Mobility Challenges:** Social settings and compromised mobility prevent effective interventions especially for women (Bajaj et al., 2013).

A Glucose trail pilot project was conducted from August 2018 through August 2019, in the suburbs of Islamabad Pakistan, one location in a semi-rural area, Pind Begwal and the second location was in a peri urban area, Bhara Kahu.

Motivation for Community of Care Pilot

Glucose Trail was founded in 2017 as a Boston based non-profit with the mission of tackling early stage diabetes through a community based solution. Cofounder Naaznin Lokhandwala MD has over 20 years of experience working as an endocrinologist and observed that tackling diabetes was about mindset and behaviour change regarding diet and exercise as much as it was about taking medicines on time. Pakistan was selected as a site to conduct a pilot due it being an example of a developing country with many rural communities that do not have access to quality medical facilities and doctors. It was also

selected due to Naaznin having initial contacts and relations with institutions there due to living her early life in Pakistan and getting her medical education from Agha Khan University in Karachi.

On the basis of Naaznin's experience and indication from research (elaborated on in the Pilot Design section), Glucose Trail developed an initial model around creating a community of care for early stage diabetes in regions where doctors and hospitals are difficult to access. This would involve training of local community volunteers as Health Care Companions, who would be responsible for helping early stage diabetes patients manage their illness, and foster positive behaviour change around diet, exercise and diligence in taking appropriate medication. These Health Care Companions would be in turn be guided by, and would relay the medical data of the patients, to doctors via a custom-designed telemedicine app.



Initial meeting between Glucose Trail, Mera Maan and Saving 9

From left to right: Abdullah Bin Abbas (S9), Faizan Tirmizi (S9), Naaznin Lokhandwala (GT), _____ (GT), Shafiq Lokhandwala (GT), Usama Javed Mirza (S9), Shahnaz Kapadia (MM)

Glucose Trail entered a partnership with two organisations, Mera Maan Private Limited and Saving 9 Educational Services Private Limited. Below is an overview of the key persons running Glucose Trail, Mera Maan and Saving 9, along with an elaboration of the role each organisation agreed to undertake for this pilot project:

Glucose Trail

Office Location: Boston, USA

Role: Oversight, Strategy and Financing

Website: <https://glucosetrail.com/>



Shafiq Lokhandwala, co-founder of Glucose trail served as the International Manager, facilitated MOU's with partner organisations, oversaw budget allocations, financed this project, oversaw, designed and financed technology in the development of Glucose Trail m-Health app.

Naaznin Lokhandwala MD served as the Chief Medical Officer, responsible for the content of diabetes educational material, templates in GT app, treatment algorithms, quality of medical care, content development for patient camps and titrated diabetes medications remotely.

Saalik Lokhandwala managed Glucose Trail website, technical consultant, deploy and implement mobile app with a remote team of developers.

Saving 9

Office Location: Islamabad City, Pakistan

Role: Pilot Project Implementation

Website: <https://www.saving9.org/>



SAVING 9

YOU DON'T NEED TO BE A DOCTOR TO SAVE LIVES

Saving 9 is a hybrid model organisation that aims to create communities of care in Pakistan around pre-hospital care for both physical and mental health emergencies. This is done by spreading first aid and mental health literacy and working closely with communities to set up locally run and owned systems that work to mitigate casualties.

Usama Javed, the founder of Saving 9 spearheaded and was responsible for operations in Pakistan, including identifying the communities, recruiting logistics personnel, local accountants, marketing personnel, translating diabetes training sessions in local language for community health care companions and content development for patient camps.

Faizan Tirmizi and Nameer Aurangzeb served as Chief of Field work, Pod Manager – responsible for recruiting health care companions (HCC), identifying reliable laboratory, local pharmacist and local grocers. Saving 9 conducted training sessions, organised patient camps and focus group sessions and served as a local resource for health care companions and the remote physician. They oversaw collection and communication of critical information including lab reports, body metrics and medication histories for mHealth remote diabetes management.

Mera Maan

Location: Bhara Kahu, Islamabad Capital Territory, Pakistan

Role: Project Design Advice, Connection with Additional Resources

Website: <http://meramaan.org/>



Mera Maan is a social enterprise that supports sustainable solutions to address social issues. Particularly, Mera Maan specialises in designing pilot projects and programs, and assisting in their scale up. It also develops training programs for literature, semi-literate and low-literate target groups, trains senior and mid-level professionals, as well as grass-roots community members.

Shahnaz Kapadia, founder of Mera Maan served as an advisor for social mobilisation, module development, training programs, scaling plans and in connecting Glucose Trail with important stakeholders in Pakistan.

Pind Begwal, a rural region on the outskirts of rural Islamabad, was selected as the pilot site for the Glucose Trail Community of Care model. This a community of about 40,000 people that are not serviced by any local qualified doctor. The nearest public hospital is a 45 minutes drive away in main Islamabad, and the nearest private hospital is very expensive compared to the local general purchasing power of the community and is a 30 minutes drive away. Further contextual details of Pind Begwal are elaborated upon on the Project Design section.

Pind Begwal was selected because of its high prevalence of patients with early stage diabetes (verified by informal site visitation and conversations with the local community and its stakeholders). Additionally, Pind Begwal is close to Bhara Kahu, where Mera Maan is based, and is the primary region where Saving 9 conducts its projects. Saving 9 was selected as the implementation partner because of its connections already built in the local community, including a Memorandum of Understanding for cooperation with Pind Begwal local Union Council government.

Pilot Design

Community of Care Model

A review of literature (e.g. Shah, Kaselitz & Heisler, 2013; Galaviz et al., 2018; Sanghani et al., 2013; Steinsbeek et al., 2012) on community diabetes interventions indicates that there is promise in group education delivered by healthcare professionals and lay community members. Having said that, most research is centred around diabetes interventions in high-income countries (which tend to also be in the clinical setting, as opposed to directly in the community), and there is a relative dearth of quality research in low-income countries. This may be due to reluctance to report null findings. This pilot conducted by Glucose Trail is intended to contribute to this nascent body of research.

Secondly, research into models involving telemedicine show that there is promise in the use of technology to connect health care workers and community members with tertiary health care services and medical experts. Technology can be of particular benefit to communities that do not have easy access to healthcare services, and where availing them through traditional in-person visits is not financially viable for many patients (Tung & Peek, 2015).

Finding diabetes early, treating it correctly is the key to longevity and a better life (Moucheraud et al., 2019; Campbell, 2001). Delayed diagnosis or sporadic, poorly planned treatment leads to irreversible complications, impairs personal productivity, places an enormous burden on dependents and care-givers. Patients who find themselves with sugars completely out of control, physically do not feel well, become helpless, fearful and hopeless. Lack of knowledge, loneliness, unpredictability, failed medical interventions and financial stress (Dagenais et al., 2016) are some of the conditions that GT will alleviate community by community. It is evident to GT, that community outreach is an integral part of a sustainable diabetes care solution (Shah, Kaseltiz & Heisler, 2013).

Glucose Trail decided to pilot the following approach to initiate a sustainable and scalable approach to addressing the issues highlighted in the previous sections:

If Glucose Trail will through a holistic and systematic approach:

- Provide high quality basic diabetes education to communities in need
- Create support systems for early stage diabetes patients through a network of Health Care Companions and partnerships with local pharmacies and grocers
- Connect the Health Care Companions with doctors via an app that will allow them to enter data and provide medical advice
- Create a system of peer-to-peer patient support that fosters behaviour change around dietary and exercise habits

Then:

- A Community of Care will be created whereby communities that are far away from hospitals will have the capacity through their citizens and institutions to deal with the onset of early stage diabetes

Pakistan is a diverse nation, with a variety of local contexts with regards to socioeconomics and culture as well as geographical terrain. Therefore, we believe that it is not possible to have a one-size-fits-all strategy to creating safer communities throughout the country. Glucose Trail will promote diabetes literacy and the creation of robust home-care support systems generally through 3 interrelated processes that attempt disentangle the 'wicked' problem (Camillus, 2008). The approach allows for continuous revision and refinement, in line with Ansell's (2011) theory of evolutionary learning/democratic experimentalism:

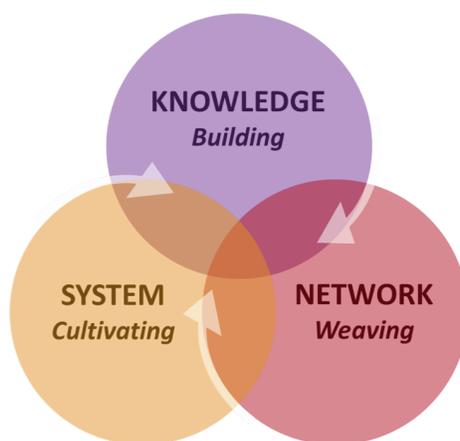


Figure 1. The GT approach to tackling the 'wicked problem' of diabetes is three-pronged.

1. **Knowledge Building** – Creating, refining and disseminating actionable knowledge of all kinds in order to ensure quality implementation and continuous improvement.
2. **Network Weaving** - Creating effective, purposeful networks between relevant individuals and organisations in order to accelerate growth, build resilience and promote self-corrective capacity.
3. **System Cultivating** - Removing political, economic, and social barriers to the creation of communities of care and replacing them with supportive systems and structures in order to nurture and facilitate reform.

Our proposed general approach allows for local adaptability (Ansell, 2011), and focuses on backwards mapped capacity building and system building (Elmore, 1980).

How this approach is adapted for the chosen pilot sites of Pind Begwal and Bhara Kahu is elaborated later below. The figure below shows the different working parts of the Glucose Trail model, and these are now elaborated upon in more detail:

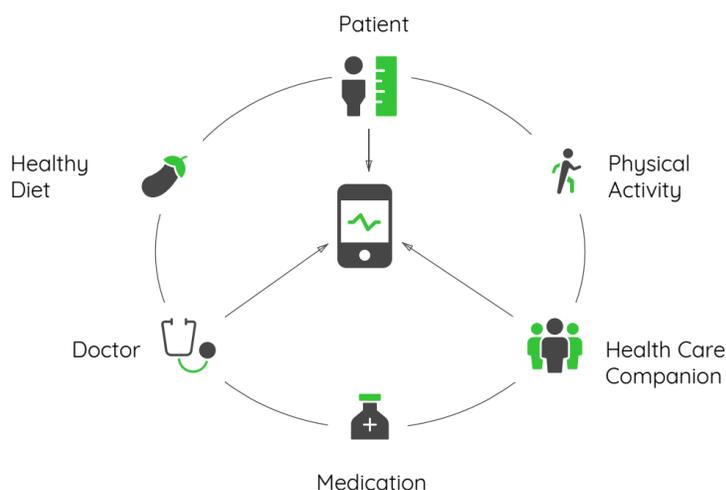


Figure 2. The different elements of the Glucose Trail model that connect together to support the patient.

- i) **Health Care Companion:** The role of a Health Care Companion (HCC) is central. An HCC is a responsible member of the community who has volunteered to take on caring for their family members and neighbours for a nominal stipend. The HCC fulfils three important tasks:
- Empower patients through education including promoting healthy diabetes diet, consistent daily physical activity, tobacco cessation and adherence to a prescribed medication schedule.
 - Provide emotional support as somebody who is close to the patient, who understands their circumstances and who can relate to “ their life” to support them.
 - Collect and enter critical, actionable patient data into a mobile app enabling remote patient assessment, follow-up and titration of treatment plan.
- ii) **A Data-Logging and Communication App:** Technology allows multiple people to connect instantly, across miles, at regular intervals. The development of a GT mobile app was conceived to enable community outreach diabetes care connecting the patient with the entire care team. Glucose Trail App henceforth referred to as the GT App that connects a remote physician, the patient and a health care companion and organises critical data required for remote care. Objective goals are checked and reviewed on a regular consistent basis to measure progress, hold the physician, the care team and the patient accountable and enable titration of diabetes medication.
- iii) **Sourcing Reliable and Affordable Pharmaceuticals and Diagnostics:** Consistent, accessible and affordable pharmaceuticals, from certified manufacturers, endorsed by Endocrine Societies, WHO guidelines for low resource settings and vetted reliable lab facilities negotiated as a bulk order on

behalf of the community.

- iv) **Community Mobilisation:** A series of diabetes camps conceived to recruit patients at baseline, enhance community participation and prioritise lifestyle as a powerful therapy. Diet and physical activity are difficult to prescribe, hence it is necessary to foster patient engagement with community support. These camps would engage local entrepreneurs such as pharmacists, grocers and recreational start-ups. Such businesses will be seeded, supported and advertised to encourage the community to effectively use their own community resources thus shifting health care expenditure from external clinics and hospitals to local community vendors.

As mentioned earlier, ultimately all of Glucose Trail's Actions tackle the multifaceted 'wicked' problem of diabetes through knowledge building, system cultivating and network weaving.

Below is an elaboration of how this has been taken into consideration in this model:

- **Knowledge Building:** Firstly, intrinsic knowledge in the community is being built through the awareness sessions regarding diabetes conducted for the health care companions, patients and their families and friends. This involves regular refreshers conducted by Saving 9 and the Health Care Companions, and also includes encourages patients to share their stories and experiences of the GT intervention with their peers in order to encourage sustainable and systemic knowledge dissemination. This also includes the lessons learnt during the pilot that are then shared among the HCC's and other stakeholders in order to promote continuous learning and improvement.
- **System Cultivating:** The 'system' being created is feedback cycle of care between the doctors, health care companions, patients and their families and friends. Cultivating this system entails fostering strong channels of communication and trust between the different actors, and this in part intended to be fostered through the GT app, and through the regular in-person meetings between the HCC's and patients and patients with other patients. The other systems that support this core include the local markets, that provide diabetic medical care products, groceries and access to exercise facilities for the community. Initiatives taken to cultivate them would include working with local pharmacies to ensure affordable stock of medicines, and working with grocers to ensure availability of ingredients for diabetes friendly meals. Though it could not be a feature of this one-year pilot, this should also include fostering of local entrepreneurship around diabetes supportive products such as exercise equipment and related support services.
- **Network Weaving:** This entails working on strategically connecting local community leaders, wealthy individuals and organisations with each other to generate buy-in and financial support for creation of a community of care. For example, allocating zakat funds for the purchase of medicines for very poor patients, and encouraging patients to take turns cooking diabetes friendly meals for each other in batches. This also includes connecting local NGO's and corporations with the project in order to encourage the channelling of corporate social responsibility and other funds into the project in order to enhance its sustainability.

Pilot Sites Pind Begwal and Bhara Kahu

Peri-urban Bhara Kahu and semi-rural Pind Begwal were chosen to pilot the Glucose Trail Diabetes Care solution. Below is a map indicating the route from main Islamabad to get to Bhara Kahu and then to Pind Begwal:

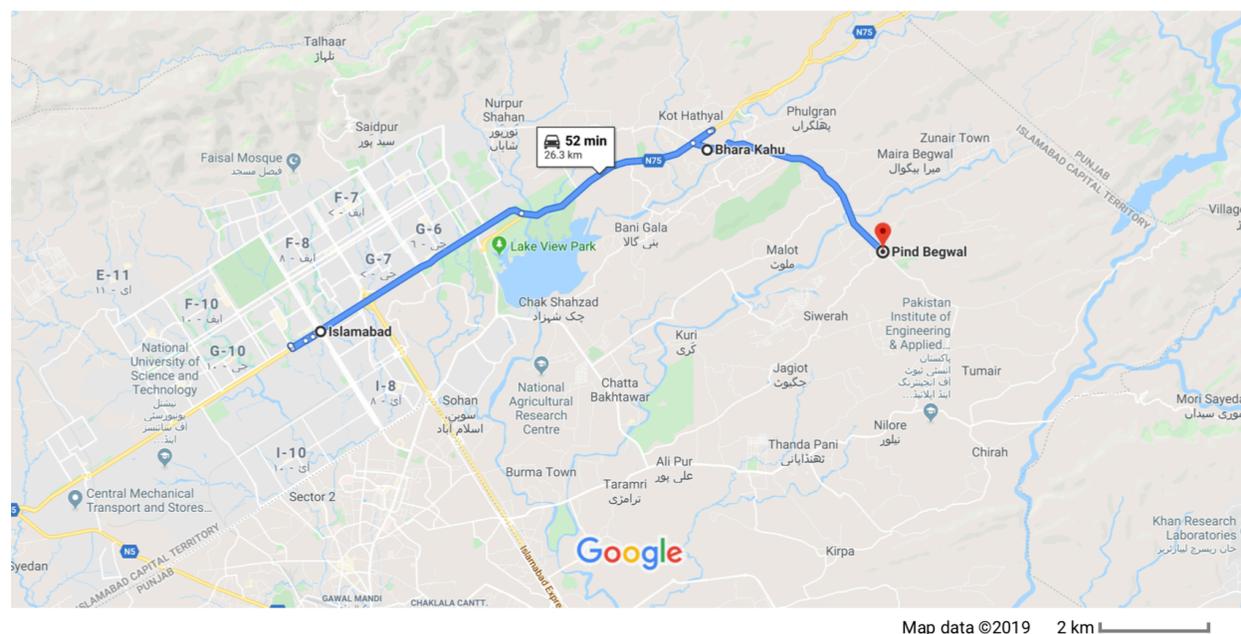


Figure 3. Google Map showing the route from Main Islamabad to Pind Begwal via Bhara Kahu

The village of Pind Begwal¹ (Union Council – 7), on the outskirts of Islamabad is a community of about 45,000 people (Pakistan Bureau of Statistics, 2017) without an ambulance system, and with poorly resourced (high doctor absenteeism and lack of medical supplies) local basic health units. Generally, the roads in the region are very rough, with frequent cracks and bumps due to rocks. People who need to go to the hospital (the nearest is 40 minutes away) are taken by bystanders/relatives via motorcycles or taxis (where these can be found).

Pind Begwal was chosen by Saving 9, when the organisation originally launched its own independent operations in 2017, because it was logistically accessible for the Saving 9 team based in Islamabad, and there has been strong receptivity from the local government. It also qualified as a region with poor diabetes literacy and inadequate medical support systems for early stage diabetes patients. The Union Council in Pind Begwal was instrumental in engaging with the community of Pind Begwal and Saving 9 worked through the local private non-profit school called House of Light to gain acceptance into the community.

¹ There is a certain region in Union Council 7 that is known as Pind Begwal with a population of about 18,500, and the administrative sector as a whole is also known as Pind Begwal. This is similar to how there is New York City in New York State.



A walk through a typical field surrounded by houses in Pind Begwal

Below is a map with the Pind Begwal region demarcated:

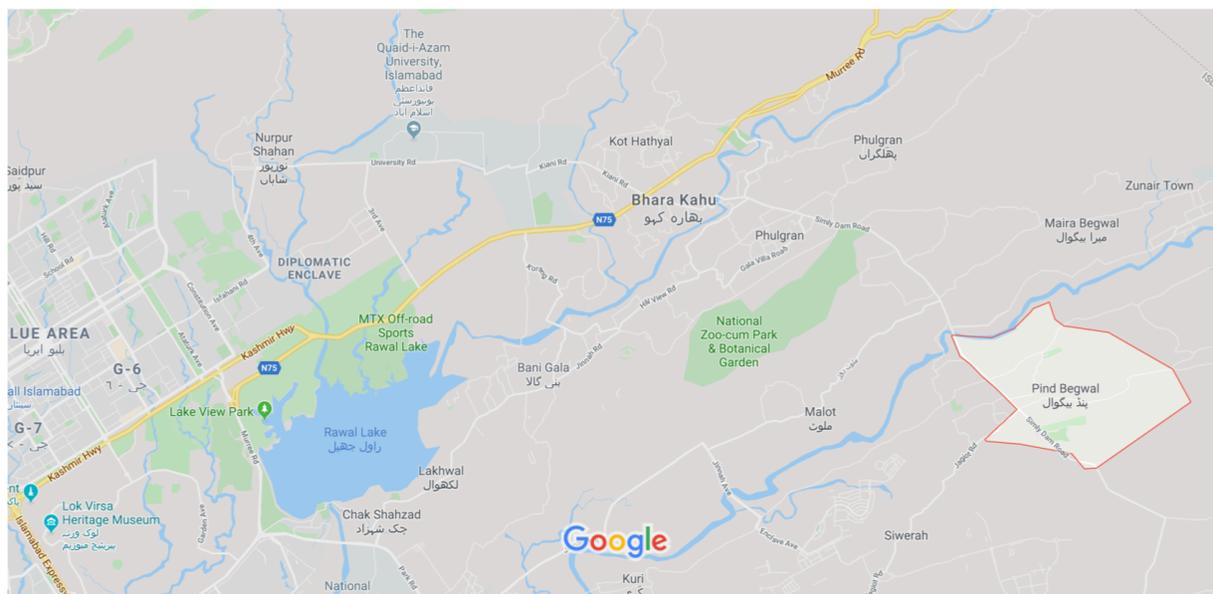


Figure 4. Google Map showing Islamabad Capital Territory with rural Pind Begwal highlighted.

The peri-urban community Bhara Kahu was chosen due to the proximity to Mera Maan. Mera Maan provided its premises free of cost for initial Glucose Trail meetings. The region of Bhara Kahu encompasses several income brackets including low income migrant populations seeking upward mobility by moving closer to a city centre. Unlike Pind Begwal, the population has access to several small pharmacies and private general medical doctors who sit in small roadside clinics. The local Health Centre helped us engage with the community of Bhara Kahu. Both these community settings were distinctly different and we set out to pilot the diabetes care solution in each community to learn how local context can influence the outcomes.

Below is a map with the Bhara Kahu region demarcated:



Figure 5. Google Map showing Islamabad Capital Territory with peri-urban Bhara Kahu highlighted.

Generally in Pakistan, diabetes is a widely recognised illness in adults, elderly and to a lesser extent in younger children. Families refer to it as “sugar” or wasting disease and report how it often leads to excessive fatigue/weakness, sores on the body, and debility. Understanding of management is very limited and reactive rather than being comprehensive and proactive. Below are some characterisations of local patient care and behaviour:

- i) Patients get their sugars checked by the local area providers sporadically.
- ii) Patients take variety of medicines (some time from more than one doctor, or local quack doctor or local remedy) or insulin sporadically.
- iii) From the medical care services that do exist, there is no emphasis on consistent care and follow up including attainment of glucose goals, medication compliance and titration.
- iv) Doctors provide no objective diet or exercise recommendations.

- v) Generally in the community there is a lack of knowledge of disease evolution and prevention of complications. Women (who mostly prepare food for the household) are more ignorant or less aware of the disease management than their male counterparts.
- vi) Family engagement in lifestyle changes or disease management is not done.
- vii) The elderly in particular struggle with disease management and their debility consumes household resources.

Pilot Methodology

Questions

This pilot project has many moving parts, and the intervention model is based on what research suggests works. It is already strongly established that early stage diabetes can be successfully ameliorated with a combination of lifestyle interventions relating to diet and exercise, along with the disciplined intake of appropriate medication. This pilot aims to assess the viability, and to gain insights into how to refine, a community based model for inculcating these lifestyle changes in patients in a peri-urban context (Bhara Kahu), where there is relative ease of geographical and financial access to doctors and hospitals, and a rural context (Pind Begwal) where it is significantly difficult to access medical services due to financial constraints and distance.

Some specific research questions include:

1. How do technology innovations like doorstep “Endocrine Expertise” improve diabetes management?
2. Are out-reach workers able to bridge the gap between prescribed medications and adherence to the care plan and lifestyle intervention?
3. The effectiveness of local intervention compared to traditional clinical care?
4. The cost of local intervention compared to traditional clinical care?
5. What is the sustainability of the outreach model and technology innovations?
6. What is the change in diabetes knowledge in the community?

Below is a diagram that shows GT's intervention design as a process with inputs, actions, immediate outcome and long-term impacts. It is the Actions that are being studied in this pilot:

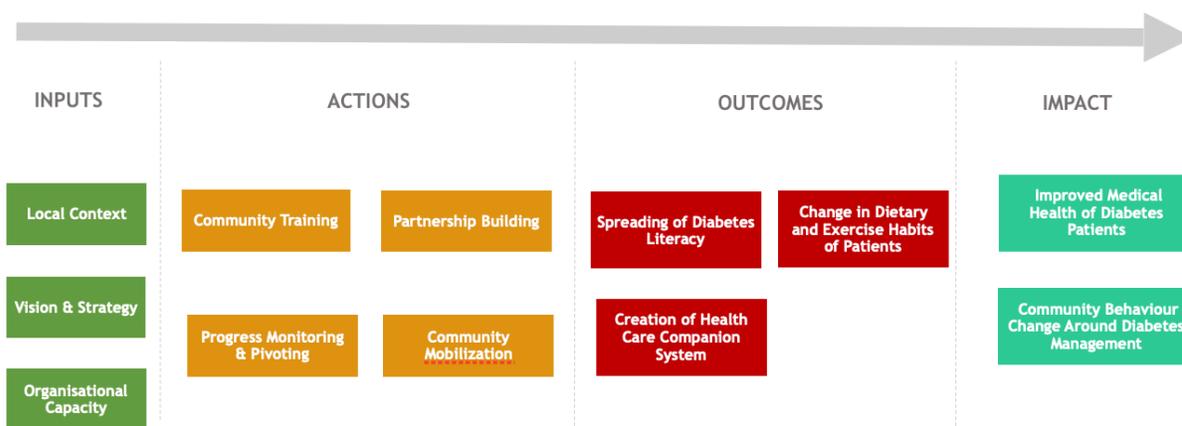


Figure 6. Glucose Trail's pilot intervention model adapted for Pind Begwal and Bhara Kahu and presented as a log frame

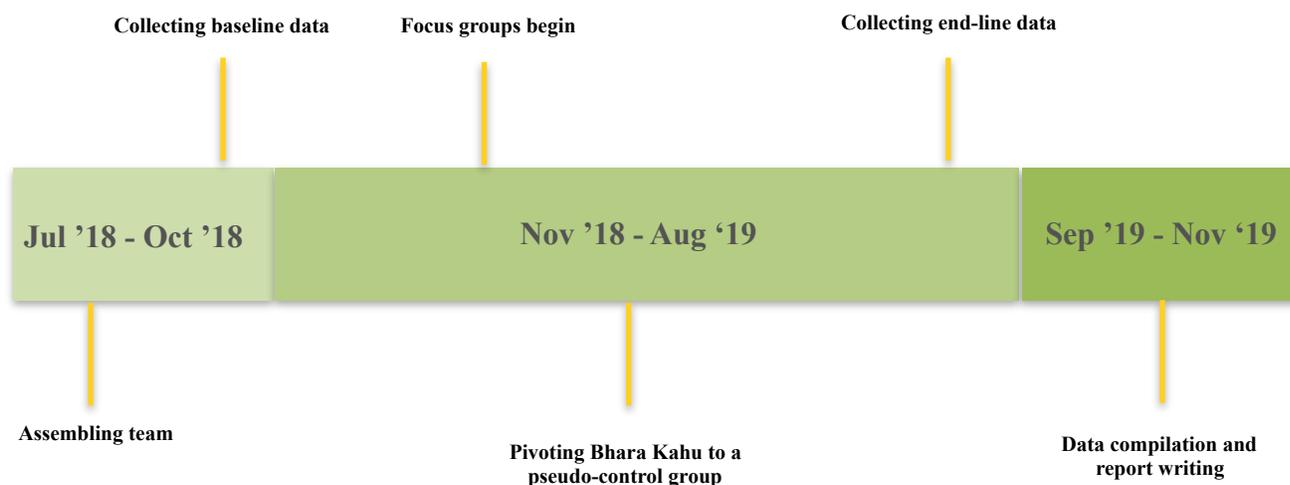
In the Inputs section, 'Local Context' refers to given socio-economic, cultural and geographical dynamics and elements of the local communities. These inevitably play a role in local lifestyle, including pertinently diet and exercise norms. This also includes general access of the community to medical services e.g. Pind Begwal's population has significant geographic and economic challenges to quality medical care access. 'Vision and Strategy' refers to the Glucose Trail model itself as it is pre-designed as elaborated in the previous Community of Care Model section. 'Organisational Capacity' refers to the collective resources (funding, connections, human resource, expertise) mobilised by Glucose Trail together with its partners Saving 9 and Mera Maan.

The Actions section refers to the actual interventions taken during pilot implementation. 'Community Training' refers to all the initiatives taken to promote awareness of diabetes in the community among the pertinent stakeholders e.g. the patients, their families and the Health Care Companions. 'Partnership

Building' refers to building strategic relationships and weaving networks with local pharmacies, grocers, influencers, and other local organisations. 'Community Mobilisation' refers to all the medical camps and other events and meetings initiated in order to build strong community of care connections that ultimately benefit the patients. 'Progress Monitoring and Pivoting' refers to the monitoring and evaluation mechanisms put in place to ensure that the intervention is going on track and that are enhanced through the GT app. Pivoting refers to the inevitable adjustments in approach that occur as unexpected challenges in the field occur during the process of implementation.

In the short term the envisioned outcomes include an increase in diabetes awareness among the pertinent community stakeholders, a sustained community of care of around early stage diabetes and behaviour change in the patients regarding their dietary and exercise practices. In the long term, it is hoped that this will ultimately result in improved medical outcomes for the patients as measured by their HBA1C's and the community adopting practices and disseminating knowledge that ultimately work to reduce the number of new cases of diabetic patients.

Pilot Intervention Details



In summary, the pilot began with recruiting Health Care Companions (HCC's) and then conducting medical camps to find patients. Th HCC's were trained in basic pre-hospital care management of early stage diabetes, and in the use of the Glucoses Trail APP. Bhara Kahu was eventually aborted as an intervention site, and the patients from that region were considered a pseudo-control group. A successful innovation along the way that was introduced was patient focus-groups. They increased feelings of a sense of community, and increased the morale of the HCC's. The HBA1C's, along with complimentary

metrics such as weight and waist lines, of the patients were measured at the start and at the end of the pilot. Below key parts of the pilot intervention elements are elaborated upon:

a) COMMUNICATIONS: BUILDING AN APP

A community outreach solution required connecting with each other in a purposeful, consistent way. Technology is one of those miracles that can connect us instantly, across miles in very objective ways. The first iteration of the Glucose Trail mobile APP (GT APP) was rolled out in August 2018. It was downloaded from Google Play Store on 3G-4G Android mobile devices. The App connected a remote diabetes physician, the patient and a health care companion. It enabled entry of critical patient information at intake by the local, literate health care companion, which was then accessed by the remote diabetes physician for treatment planning. The treatment intervention was then entered into the app by the remote diabetes physician. The local health care companion reviewed the instructions conveyed in the app and communicated the treatment plan to the patient. This communication loop between Patient to Health Care Companion to Remote Diabetes Physician- back to Health Care Companion back to Patient, repeated itself via the APP through the duration of the Pilot project. In so doing the app not only connected the care team but organised all the critical objective data required for remote care, to maintain consistent follow-up and enable objective goals to be measured and the care plan titrated till goals were met.

b) COMMUNITY MOBILISATION

i) Communities Identified in suburbs of Islamabad Pakistan

As elaborated earlier, peri-urban community Bara Kahu and semi-rural community Pind Begwal were chosen to pilot the Glucose Trail Diabetes Care solution. The village of Pind Begwal (Union Council – 7), on the outskirts of Islamabad is a community of about 45,000 people (Pakistan Bureau of Statistics, 2017) without an ambulance system, and with poorly resourced (high doctor absenteeism and lack of medical supplies) local basic health units. Generally, the roads in the region are very rough, with frequent cracks and bumps due to rocks. People who need to go to the hospital (the nearest is 40 minutes away) are taken by bystanders/relatives via motorcycles or taxis (where these can be found). Pind Begwal was chosen by Saving9 because it was logistically accessible for the Saving 9 team based in Islamabad, and there has been strong receptivity from the local government. It also qualified as a region with poor diabetes literacy and inadequate medical support systems for early stage diabetes patients. The Union Council in Pind Begwal was instrumental in engaging with the community of Pind Begwal.

The peri-urban community Bhara Kahu was chosen due to the proximity to Mera Maan. Mera Maan provided its premises free of cost for initial Glucose Trail meetings. The region of Bhara Kahu encompasses several income brackets including low income migrant populations seeking upward mobility by moving closer to a city centre. Unlike Pind Begwal, the population has access to several small

pharmacies and private general medical doctors who sit in small roadside clinics. The local Health Centre helped us engage with the community of Bhara Kahu. Both these community settings were distinctly different and we set out to pilot the diabetes care solution in each community to learn how local context can influence the outcomes.

ii) Explored Resources in each community

Glucose Trail and Saving 9 Team first visited each community site to determine the local resources available in each community.

Dietary and recreational sources were first explored. Pind Begwal was a more rural setting. 2-3 local vegetable vendors, grocers sourcing flour and grains and 2-3 general stores were identified. There were scant restaurants or food vendors and it was apparent that most community members ate home cooked food. There were open paths and spaces for walking but due to cultural barriers most of the women were limited to their own homes/ neighbours or relatives homes. Homes were spacious and had room for walking in place indoors or outdoors.

Bhara Kahu had several small roadside vegetable vendors, several small to large general stores, snack shops, food vendors/restaurants in a variety of price ranges. Low income population lived in small living spaces, congested, mostly in apartment buildings. Lanes were narrow and limited space for walking.

Pharmacies were explored next. Pind Begwal had only one pharmacy and this was newly established. The pharmacist was just stocking his shelves when we visited. The core diabetes medications including metformin, sulphonylureas, gliptins and insulin were available at the pharmacy. Bhara Kahu had several small and larger pharmacies and most stocked core diabetes medications and insulin.

Diagnostic facilities were explored. There was no lab facility in Pind Begwal. There were smaller lab facilities in Bhara Kahu but on meeting with a local prominent doctor in Bhara Kahu, we were cautioned on the validity of the local labs. Mera Maan therefore facilitated all diagnostic lab testing through Islamabad diagnostic Centre who subsidised the cost of the labs by over 50%.

c) COMMUNITY TRAINING

i) Created the care team

Saving 9 first identified the Pod manager. They oversaw the entire pilot project from engaging with the main stakeholders in the community, and oversaw the operations required to roll out pilot project. Saving 9 also appointed a photographer to document the pilot project through pictures/ videos. The Pod manager's role was supported by members of the Saving 9 team.

The Pod manager identified a HCC Admin in each community. The need for this role became apparent 3 months into the pilot. This individual was local to each community and worked closely between the Pod



Manager and the HCC's as an ongoing resource to facilitate and oversee accurate data entry into app, supervised and monitored HCC performance. These individuals expressed willingness to be trained in diabetes management skills, interact with Glucose Trail App and fulfil this supportive role for a small stipend.

Criteria for HCCs:

- Up to matriculation level education.
- Must be able to operate a smart phone/ digital tablet.
- Must live physically close to the patients that they serve and are motivated to learn about diabetes management because either themselves or their family members/ neighbours have diabetes.

A HCC managed between 3-14 patients each and they were paid a stipend per patient per month.

Number of HCC's trained in PB	7, along with an additional HCC admin
Number of HCC's trained in BK	4, where one of the HCC's took on the role of being an admin as well
Total HCC's Trained in PB and BK	11

In Pind Begwal, we met with the Principal of The House of Light School, who facilitated a meeting on the school premises with the teachers and teachers' relatives. Seven HCC's were initially recruited in Pind Begwal through the school.

In Bhara Kahu, 4 health care companions were recruited through the local health centre. These individuals did not have any medical degree but were working at the health centre to support public health initiatives.

Attrition	
Pind Begwal	<ul style="list-style-type: none"> HCC Admin Adeela started on Nov 2018 and then left in April 2019 due to family circumstances HCC Nazish and Rabia started on August 2018 and were then let go from the project on September 2018 <p>Patients under Nazish and Rabia were spread out among the remaining HCC's</p> <p>Total number of HCC's at conclusion of pilot in Aug '19 were 5</p>
Bhara Kahu	<p>4 HCCs were terminated by February 6, 2019 as they were not fulfilling core functions and were unwilling to continue with the stipends budgeted: patients under their care were decidedly considered as a control group</p>

As of Jan 27, 2019 active HCC's and patients under care were as below:

Number of Patients Under Each HCC				
	HCC Name	No. of Patients	Active Aug 2019	Reason
PB	Noshia	14	Yes	
PB	Ansa	9	Yes	
PB	Samina	5	Yes	
PB	Zobina	9	Yes	
PB	Nazish	7	No	Left herself

PB	Nadia	4	Yes	
In total 6 HCC's in Pind Begwal, and 48 patients				
BK	Shazma	9	No	Let go
BK	Iqra	7	No	Let go
BK	Saima	9	No	Let go
BK	Fatima	10	No	Let go
In total 4 HCC's and 35 patients				

Naaznin Lokhandwala (MD certified by PMDC in Pakistan and based in Boston MA, Board certified in Internal Medicine , Endocrinology Diabetes & Metabolism) provided diabetes expertise through the App based on best practices in diabetes care in low resource settings. Affordable therapy in accordance to Endocrine Society in Pakistan/ International guidelines was prescribed.

Saving 9 educators trained the health care companions. These educators were given comprehensive instruction in diabetes care based on a curriculum set by Naaznin Lokhandwala MD. The content of the curriculum was limited to the knowledge and diabetes self management skills that is routinely imparted to a literate diabetes patient. The educators relayed this same information to the HCCs in a culturally contextual way over 3 sessions at a location within each community. In Pind Begwal it was at the school, in Bhara Kahu at the health centre.



HCC's practicing administering insulin during their training from Saving 9

The content in the training sessions included basic diabetes knowledge, recommended plate diet, physical activity, familiarised them with core medication names/ doses, how to administer insulin, how to measure glucose/ weight waist circumference, how to use an automatic BP & data entry into app and hypoglycaemia prevention. Sessions were conducted in Urdu over slides sets, through practical demonstrations and hands on training.

Each HCC was equipped with a glucose meter, lancets, glucose strips, Automatic BP meter, weighing scale, Tape measure. They had their personal digital devices (mostly 3G mobile phones) with a data plan. Data plans were partially supported through the Pilot. Each HCC was entered into the APP.

d) PATIENTS RECRUITED

Inclusion Criteria: Patients with an established diagnosis of diabetes defined by a HBA1C > 6.5 & fasting glucose > 126 or random glucose > 200.

Exclusion Criteria: Diabetics with end stage complications (ESRD, CHF, foot ulcerations/ amputations, proliferative retinopathy) and diabetes in pregnancy and non-ambulatory patients and patients with advanced medical co-morbidities requiring frequent hospitalisation such as active cancer, advanced liver disease etc.

Recruitment camps: We intended to recruit 50 patients from each community. After considering options in recruiting diabetes patients, it was decided that each HCC would personally invite and convince their relatives, neighbours and friends known to have diabetes or suspect they may have diabetes to come to the recruitment camp and participate in this treatment. Effort expended included coaxing over WhatsApp groups and patients were incentivised to join by covering the cost of their labs and providing refreshments at the camp.

The camp sites were carefully chosen and were held at a convenient location in each community.

Four Patient Recruitment Camps were held as shown in the table below:

Patient Camp Recruitment Table							
No.	Date	No Diabetes	Pre Diabetics	Diabetics	Total	% Diabetics	Area
1	19/08/2018	6	6	33	45	73.33	PB
2	02/09/2018	11	7	30	48	62.5	BK
3	28/10/2018	8	5	17	29	58.60	PB
4	23/12/2018	0	1	9	10	90	BK

Key activities at the recruitment camps included mobile phlebotomy wherein all individuals who were willing to participate in the pilot had baseline lab tests including HbA1C and creatinine and glucose finger-stick tests. Due to a limited budget labs were limited to these critical tests. HBA1C confirmed diabetes and indicate the level of hyperglycaemia in the preceding 3 months and creatinine helped guide safe treatment planning as some diabetes medications are contraindicated with chronic kidney disease.

At the fourth camp it was decided to screen each potential participant with a finger-stick glucose prior to having labs done. Those individuals already taking diabetes medications or individuals not on diabetes medications but with a finger-stick glucose > 126, went onto to have their labs tested.

Saving 9 educators gave a general presentation to all attendees on diabetes, merits of early treatment, prevention of complications.

Patient contacts were obtained and all patients were informed that if their lab tests confirmed diabetes they will be invited to come under the care of Glucose Trail through their respective HCC. Patients had been encouraged to bring their medications to the recruitment camp but most of them did not.

The recruitment camp was organised in Stations with a trained HCC or Saving9 Staff managing a station assigned to them. Stations included:

Station 1: Finger-stick Glucose was obtained and recorded on paper

Station 2: Entry of current medications, doses and frequency including insulin (this did not occur as most patients did not bring their medications)

Station 3: Patient profile was created in APP and assigned to an HCC in the APP. This was done by Saving 9 staff.

Station 4: BP was measured and recorded on paper

Station 5: Waist circumference measured and recorded on paper

Station 6: Height and weight measured and recorded on paper

Station 7: labs were drawn by mobile phlebotomist from Islamabad Diagnostics

All the data collected at the camp was recorded in Google/ Excel spreadsheets and entered into the APP at a later date. Medication records were obtained by visiting patients homes, through WhatsApp pictures and eventually entered into the APP.



Blood pressure checking



Measuring weight



Recording patient height



Taking glucose readings

e) DOCTOR INTERVENTION

The remote Doctor (diabetes specialist) reviewed the patient data as it became available and the first treatment interventions were entered into the APP by November 2018.

Conveying intervention

HCC's with the help of HCC admins/ Saving 9 staff reviewed doctor intervention in the APP which included medication dose and frequency, general diet and exercise recommendations and next recommended follow-up. These recommendations were listed in Urdu in the App and were conveyed to the patient as soon as possible by visiting them at home or during a focus group session or calling them on their mobile phones directly. Patients obtained prescribed medications through their local pharmacy and paid for their own medications. If a patient could not afford medications prescribed, community members raised money to help pay for the medications.

f) HOME VISITS/ FOCUS GROUPS

HCC's visited patients at their homes/ in focus groups under their care every 2-4 weeks. Follow up encounters were performed and patient data including current medications, BP, weight, and glucose readings were entered into the APP. Focus groups were used to reinforce compliance with medications including insulin, foundational diet and physical activity. In addition, these groups addressed local challenges including emotions, fears, and affordability concerns. They also shared meal plans, shared stories, built friendships, innovated local solutions and created a supportive circle of care.

g) REMOTE FOLLOW-UP CARE

Doctor (Naaznin Lokhandwala MD) reviewed updated encounter and titrated therapy according to updated data by re-entering a new intervention into APP. By January 2019 it became clear that the Bhara Kahu HCC's were not performing adequately and Glucose Trail disengaged with Bhara Kahu after paying the HCC's their stipends up to January, thanking them for their services and advising the patients under their care to seek routine diabetes care. The Bhara Kahu patients were informed that their labs would be repeated by August 2019. From January 2019 patients in Pind Begwal remained in the intervention group, and it was decided patients in Bhara Kahu would serve as a control group.

The HCC's in Pind Begwal continued to review updated interventions and conveyed instructions to patients as soon as possible by phone or by visiting the patient at home. This encounter - intervention cycle was repeated every 6- 8 weeks approximately and 4 cycles occurred between December 2018 to August 2019 for the patients in Pind Begwal.

h) CLOSING DIABETES CAMP

Patients in control and treatment groups were contacted and invited to a closing camp to repeat 1 year follow-up lab tests by July 2019.

Patients in treatment and control group had both HBA1C and creatinine levels retested by Islamabad diagnostics. 37 patients in Pind Begwal came for lab tests and 6 patients in Bhara Kahu had their labs tested.

Patients having their HBA1C tests done at a medical camp in Pind Begwal



Qualitative questionnaires were conducted for both HCCs and Patients at the conclusion of this pilot and responses were translated into English, detailed in this report.

Pilot Outcomes

The Data

In Pind Begwal 47 diabetes patients joined Glucose trail; 38 women and 9 men. 44 of these patients remained under the care of Glucose Trail from December 2018 to August 2019. 41 of these 44 patients came for final testing.

In Bhara Kahu 35 patients joined Glucose Trail till January 2019. Thereafter patients in Bhara Kahu were requested to return for follow-up blood tests in August 2019 but did not remain under the care Glucose Trail.

Diabetes Patients Tracked by Area and Gender Breakup on Aug 27th 2019			
Area	No. of Females	No. of Males	Total
BK	25	10	35
PB	38	9	47
TOTAL	63	19	82

The age ranges of the above patients was from 29 to 75 years of age.

Pind Begwal Patients and Attrition:

Of the 47 patients found to have diabetes in Pind Begwal 44 were followed

Of the 44 patients followed 41 came for final testing - One was dropped because blood sugars were good and had an initial HbA1C of 6.5, one dropped out on her own in April 2019 for unclear reasons, and one had a significantly elevated HBA1C to start with, glucoses improved under care of GT, and did not require insulin which was initially prescribed but did not show for final testing.

Bhara Kahu Patients and Attrition:

Of the 35 patients recruited only 6 showed for final testing because of lack of contact.

Patients Who Came for Final Testing		
BK	PB	Total
6	41	47

The cohort of 47 patients who had baseline lab testing and final lab testing were further analysed:

Tobacco Use: 13 patients disclosed that they regularly use tobacco

Occupation: Men occupations included a driver, shopkeeper, guard, office job and driver and some retired. Majority of women were housewives and 1 patient was a health worker (not a Glucose Trail HCC) herself.

Number of Patients on Insulin or Prescribed Insulin:

There were 2 patients among these 47 patients who were taking insulin at Baseline. During the course of the pilot, 7 patients were prescribed insulin. 5 of the 7 patients started taking insulin. Hence a total of 9 patients were in need of insulin and 7 out of 9 patients actually took insulin. Starting insulin was the most challenging medication to introduce in diabetes therapy. For some of these patients it took several meetings by the HCC, with the support of other community members to convince them to start insulin. 6 out of 7 patients were prescribed basal NPH, not mixed insulin, in combination with oral medications to reduce the risk of hypoglycaemia.

Insulin Patients Overview

Insulin Baseline	Insulin Prescribed	Taking Insulin	Not Taking	Insulin Need
2	7	7	2	9

Average Patient Weight

Baseline Average Weight

69.30 kg

Final Average Weight

68.04 kg

Patient HBA1C's:

Baseline average HBA1C and final average HBA1C measurements for patients assigned to each HCC in PB and in BK were calculated and compared. In PB, these 41 patients under the care of 5 HCC's had an average baseline HBA1C exceeding 9.0% under each HCC. The average final HBA1C declined for all HCC's in PB, some faring better than others.

Conversely 6 patients in Bhara Kahu under the care of 3 HCC's, had an average baseline HBA1C exceeding 7.5 % and the average final HBA1C increased for all 6 patients.

These results demonstrate an improvement in diabetes in patients in PB over the course of 9 months under the care of Glucose trail and worsening of diabetes in patients in Bhara Kahu who did not remain under the care of Glucose trail. Observing the change in average HBA1C in patients under each HCC, suggested that some HCC's were more effective in supporting their patients.

HCC	Patient Count	Average Start HbA1C	Average End HbA1C	Avg of Diff in HbA1C
BK	6	9.30	10.67	1.37
Fatima	2	7.55	9.85	2.30
Iqra	3	9.37	10.47	1.10
Shazma	1	12.60	12.90	0.30
PB	41	10.41	9.56	-0.85
Ansa	11	10.51	9.60	-0.91

Nadia	2	12.05	7.60	-4.45
Noshia	14	9.89	9.79	-0.11
Samina	5	11.64	10.94	-0.70
Zobina	9	10.03	8.83	-1.20
Grand Total	47	10.27	9.70	-0.56

As interventions were entered remotely into the APP, these interventions needed to be conveyed to the patients through their respective HCC's. Likewise, HCC's were tasked with entering follow-up patient data into the APP which would lead to another intervention. Apart from interacting with patients individually, meeting with their patients in a group setting, "a focus group", became a more efficient and effective way of conveying and obtaining information. Focus groups were held at an HCC or patient home. Meeting as a group fostered a deeper community connection where diet, exercise, adherence to medications, challenges and fears were discussed in a supportive setting. 22 focus groups were held during the course of the pilot.



Focus group being conducted with patients

The table below demonstrates the number of focus groups held by each HCC:

Details of Focus Groups Conducted in Pind Begwal			
HCC	No. of Focus Groups	Date /2019	Patients
Ansa	3	26th March	5
		31st March	
		30th June	
Nadia	1	14th. April	3
Noshia	6	27th March	7
		5th April	
		21st April	
		28th June	
		24th July	
		10th Aug	
Zobina	6	23rd March	7
		29th March	
		5th April	
		11th April	
		21th April	
		15th June	

Data in the APP was extracted to demonstrate the number of interventions entered for each of these 47 patients. The starting HBA1C and ending HBA1C for each patient was listed and compared. For patients in Bhara Kahu with only 1-3 interventions the HBA1C stayed the same or increased. For patients in Pind Begwal with 4 to 11 interventions (average of 7 interventions) the HBA1C levels improved in 26 out of 41 (63 %) of the patients. What was more notable is that 1 HCC (Noshia) in Pind Begwal who oversaw 14 patients skewed the data as the patients under her care did not improve or worsened despite an average of 9 interventions entered for each of her patients in the APP. The remaining 25/27 (92 %) patients distributed between the 4 other HCCs in Pind Begwal showed a decline in their HBA1C's by the end of

the pilot. On reviewing doctor comments in the APP on Noshia's patients, it was evident that information was not being entered and conveyed accurately between her and her patients. The glucose data remained high and poorer outcomes were expected in her group of patients even before the final HBA1C was measured.

HCC	Patient Name	Starting HBA1C	Ending HBA1C	No. of Interventions
Ansa Bibi PB	Akseer Bibi 55 PB	12.50	11.20	11
	Arbi Khatoon 62 PB	11.60	11.20	11
	Badra Qauam 39 PB	9.00	9.10	10
	Fareeda Bano 68 PB	11.10	10.40	11
	Fareeda kousar 38 PB	8.90	7.10	11
	Gulam Sahbir 46 PB	10.10	7.90	7
	Kalsoom bibi 75 PB	12.20	12.30	8
	Qudrat Jan PB	6.80	7.50	5
	Saeed Ahmed 70 PB	11.10	9.20	8
	Zahida bibi PB	12.40	11.20	4
	Zubaida Ghaffar 63 PB	9.90	8.50	7
Fatima BK	Mir Jalal Shah 54 BK	7.30	12.00	1
	Rubina Shamriaz 39 BK	7.80	7.70	1
Iqra Abbasi BK	Khalida Parveen 53 BK	8.80	8.80	3
	Shahida Parveen 50 BK	11.20	12.30	2
	Zahida Irtaza 50 BK	8.10	10.30	2
Nadia PB	Shameem Akhtar 53 PB	14.00	6.60	9
	Shehreen 29 PB	10.10	8.60	10

Noshia Bibi PB	Aurangzeb 61 PB	10.80	12.00	11
	Farzana Bibi 36 PB	11.60	9.90	10
	Fazeelat Jaan 71 PB	8.90	9.00	11
	Fouzia bibi 38 PB	7.70	7.60	9
	Gulnaar Bibi 55 PB	10.60	9.80	10
	Khalid Hussain 39 PB	11.70	12.00	8
	Khursheed Bibi 55 PB	16.90	6.40	8
	Qaniz Akhtar 60 PB	11.50	11.80	9
	Rashida Bano 45 PB	10.10	12.10	9
	Shahida Ashraf 45 PB	8.40	12.40	8
	Shakat Hussain 42 PB	9.40	10.10	8
	Sughra Bibi PB	6.00	6.40	4
	Suraiyah 65 BK	8.10	10.40	7
Zuvida bibi 80 PB	6.80	7.10	8	
Samina Afzal PB	Mahfooz bibi 75 PB	8.80	7.60	8
	Nasim Ahmed 52 PB	14.90	14.00	6
	Rehana bibi 43 PB	8.50	8.40	7
	Shameim bibi 53 PB	14.00	12.30	10
	Zaiba Rizwan 40 PB	12.00	12.40	7
Shazma Haroon BK	Naheed 42 BK	12.60	12.90	1
Zobina Shaheen PB	Gulshan bibi 40 PB	12.00	10.90	10
	Jinda khan 65 pb	9.20	10.00	8
	Kamran Akhtar 32 PB	7.80	7.70	9
	Khusnood bibi 45 PB	6.80	7.10	9
	Musarat bibi 40 PB	12.00	9.60	9

Naseem bibi 45 PB	12.30	11.00	11
Parveen Akhtar 50 PB	10.80	8.60	10
Tasleem Akhtar 51 PB	10.40	8.80	10
Zahida Bibi 48 PB	9.00	5.80	7

Glucose data for each patient was extracted from the APP. Each patient in Pind Begwal had their glucose checked between 18-40 times during the course of the pilot (1 patient on insulin had glucose checked 70 times). In Bhara Kahu, the 6 patients analysed had their glucose checked 1-8 times. Glucoses were checked pre-meals or post meals. Detailed in the following table, average glucose levels were calculated over 3 periods, Aug- Dec 2018, Jan- April 2019, May-Sep 2019 for each patient along with HBA1C change. An unchanged or higher HBA1C was predictable based on serial average glucose readings which increased. It was predicted that patients under Noshia's care were expected to have the same or increased final HBA1C results based on serial glucose levels and this was consistent with the final testing results. Likewise, it was predicted that patients under Zobina's care would have the same or lower HBA1C results which was again consistent with final HBA1C testing. This data supports that glucose testing is an important adjunct in diabetes care and even limited but consistent glucose testing in low resource settings can help intensify efforts when glucoses are not meeting goals.

Patients Organised by HCC	Aug-Dec 2018 Avg Blood Sugar Rdg	No. of Rdgs	Jan-Apr 2019 Avg Blood Sugar Rdg	No. of Rdgs	May-Sep 2019 Avg Blood Sugar Rdg	No Rdgs	Total Rdg	HbA1c Change
Ansa Bibi PB	215	28	243	88	201	133	249	-0.9
Akseer Bibi 55 PB	235	3	254	6	254	16	25	-1.3
Arbi Khatoon 62 PB	234	4	231	8	241	12	24	-0.4
Badra Qauam 39 PB	166	3	232	8	176	10	21	0.1

Shahida Parveen 50 BK	334	1	244	1		2		1.1
Zahida Irtaza 50 BK	161	1	263	1		2		2.2
Nadia PB	200	6	178	12	185	24	42	-4.5
Shameem Akhtar 53 PB	190	3	140	6	139	12	21	-7.4
Shehreen 29 PB	209	3	217	6	231	12	21	-1.5
Noshia Bibi PB	261	63	271	208	261	174	445	-0.1
Aurangzeb 61 PB	336	7	286	17	283	15	39	1.2
Farzana Bibi 36 PB	228	7	252	17	280	14	38	-1.7
Fazeelat Jaan 71 PB	229	4	282	21	242	15	40	0.1
Fouzia bibi 38 PB	199	3	213	17	157	13	33	-0.1
Gulnaar Bibi 55 PB	231	4	258	14	271	14	32	-0.8
Khalid Hussain 39 PB	372	4	282	15	240	9	28	0.3
Khursheed Bibi 55 PB	231	2	258	14	167	12	28	-10.5
Qaniz Akhtar 60 PB	269	4	263	15	338	13	32	0.3

Zobina	250	85	229	103	212	114	302	-0.9
Shaheen PB								
Gulshan Bibi			323	4	238	14	18	-1.1
40 PB								
Jinda Khan	208	47	220	12	197	11	70	0.8
65 PB								
Kamran	237	5	165	18	149	11	34	-0.1
Akhtar 32 PB								
Khusnood	205	3	154	11	172	12	26	0.3
Bibi 45 PB								
Musarat Bibi	308	9	230	15	169	13	37	-2.4
40 PB								
Naseem Bibi	417	7	335	9	261	13	29	-1.3
45 PB								
Parveen	358	5	208	9	225	13	27	-2.2
Akhtar 50 PB								
Tasleem	249	5	304	15	263	17	37	-1.6
Akhtar 51 PB								
Zahida Bibi	242	4	213	10	195	10	24	-3.2
48 PB								
Grand Total	245	202	257	464	232	501	1167	-0.6

The spread of some form of diabetes literacy amongst non medical individuals over the course of this pilot is notable. Including the Saving 9 team (at least 7), community members tested (about 132), health care companions/ admin trained (12) and ancillary community members present at focus groups (4), a total of at least 155 individuals were contacted by this pilot effort.

Costs Expended for Project July - August 2018

Category	PKR Spent	% of Total	PKR Billed S9
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Glucose Trail		1,698,275
Equipment	120,925	6.75%
HCC Stipend	341,650	19.07%
Lab tests	133,500	7.45%
Patient Camp	51,000	2.85%
Printing	90	0.01%
Saving 9 Services	1,100,000	61.41%
Transport	44,000	2.46%
Grand Total	1791165	1698275

Findings from Surveys and Questionnaires Administered to HCC's and Patients:

The Saving 9 team conducted a basic interview with the HCC's (in Pind Begwal) in the month of February 2019, about three quarters through the pilot. Below are the questions that were asked:

- Q1. How did you first learn about Glucose Trail?
- Q2. Why did you decide to become an HCC?
- Q3. Did someone influence or persuade you to become an HCC?
- Q4. Did you need to ask permission from anyone?
- Q5. Did you know all your patients before you brought them to GT?
- Q6. Were you taught how to be a support to your patients? If so how?
- Q7. Did you understand how to manage diabetes?
- Q8. Did you learn what the risks of managing diabetes are? What are the top 3 risks you remember?
- Q9. Did you learn how to use the instruments Glucometer, BP meter, weighing scale?
- Q10. What feedback can you give us about any trouble you had using any of these?
- Q11. Did you learn to use the GlucoseTrail App?
- Q12. Did you enter any data into the Glucose Trail App?
- Q13. Any feedback on using the App?
- Q14. Can you name medications used to treat diabetes?

- Q15. How many times did you see a patient as an HCC in a month?
- Q16. How did the patients see your role? Were you welcome?
- Q17. Did your patients take your instructions seriously?
- Q18. How many of your patients followed through on your instructions?
- Q19. Did you feel you made a difference to the patients' life?
- Q20. Do your patients think your intervention helped?
- Q21. How did you know what the doctor had prescribed for each patient?
- Q22. Do you feel you are viewed differently in your community after being an HCC? How?
- Q23. What are the 3-5 main issues you had being an HCC?
- Q24. For each issue do you have a recommendation?
- Q25. Do you think being an HCC benefitted you?
- Q26. Do you think your patients got a benefit from your being an HCC?
- Q27. Would your patients pay to have you manage their diabetes every month?
- Q28. Would your community create a fund to pay for patients who cannot pay?

Generally the survey answers indicated that the HCC's first heard about Glucose Trail through Saving 9 and its ongoing projects in the local schools regarding teaching first aid. The HCC's all talked about how they joined the project because they felt their community strongly needed this medical support, and because they had seen their relatives suffer in silence because of diabetes. For example, one HCC said "There is a woman who does not have any son, all her daughters are married and she had to be taken to the hospital frequently due to diabetes. I wanted to help such people." The survey also validated the assumption of the team that the HCC's already knew many of their patients in advance.

The HCC's expressed their appreciation for the APP, and said that it was easier than the previous provisional system of sending the information via Whatsapp.

Regarding their patients, the HCC's generally conveyed that their patients were by and large following their treatment, with some notable exceptions. One HCC notes², for example, "... his name was _____ who had very high sugar levels. He was prescribed Insulin. At first he refused Insulin then with the help of brother _____ and _____ we convinced him to take Insulin. After 2 months of taking Insulin he was better but he decided to leave as someone from the village told him to stop taking it and now due to that decision his sugar levels are high again."

There was generally consensus among the HCC's that they feel that they are being viewed in a more positive light by the community now. One HCC said: "Yes, not only my patients but other people in my area as well come to me for help when they face a blood pressure issue or similar problems. I live in a backward area so before, patients had to go to Pind Begwal or some other area but now I have a glucometer and other apparatus so I can check for some problems." However, these findings may need to

² Names have been left out to respect patient confidentiality in this regard

be taken with a pinch of salt because Noshia, whose patients generally did not show improvements in their final HBA1C's also said: "In the start, a lot of trouble was faced. They used to fear that we didn't learn anything, and used to say that we were useless because we didn't bring medicines. However, I convinced them to give us a try and then when they saw a lot of difference in results, they were satisfied. Now they're very happy with our role." This could potentially indicate that the HCC's might have been giving optimistic answers due to local cultural norms in this regard, and because they knew that the answers would be read by the 'managers' of this project.

The HCC's general expressed that they had managed to overcome many of the logistical challenges that they were experiencing in the beginning regarding arranging visitations with their patients, however, some did still vote concerns regarding commuting to their patients being a challenge for them to manage on the basis of stipend pay and their social mobility due to their gender.

Finally, regarding the patients finding solutions to financial challenges with the purchasing of medicines, they had mixed opinions. One HCC said (regarding the patients financially pooling for medicines): "It's up to the mentality of the people as most of them will say as to why they should put their money into the fund plus they will have this in the back of their mind that I who is putting up a fund is earning a lot of money that is why I am doing this thus they will refuse to put their money in the fund." Whereas another HCC said "Yes, we can. If everyone contributes even a little, we can collect a lot. When discussed in the community, those who could afford to did agree they'll pay."

The patient questionnaire was as follows (administered to the Pind Begwal patients in April 2019):

- Q1. How do you know you have diabetes?
- Q2. Is diabetes curable?
- Q3. Are you at an increased risk of diabetes if your family member has diabetes?
- Q4. Can diabetes be spread through contact/ Is it viral?
- Q5. What is the effect of tobacco on diabetes
- Q6. What is the effect of weight on diabetes?
- Q7. What food should you avoid when you have diabetes and why?
- Q8. Does exercise have any effect on blood glucose? If so, what?
- Q9. What complications can develop with diabetes?
- Q10. Are the complications preventable? How?
- Q11. Can you stop taking medications? Why?
- Q12. Does checking your glucose at home help in managing your diabetes?

Generally the patients gave the correct (albiet very brief) answers to the questions asked, indicating that they did generally realise that diabetes is not infectious, and that it can cause significant problems to different body systems if allowed to worsen. They also appreciated the value of exercise and that it is important to be regular with medications. Of particular interest, more than 50% of the patients said that they did not know that they had diabetes until they went for a general check up.

Discussion

Positive Outcomes

The important outcomes from this pilot effort can be summarised under value, growth and impact.

a) VALUE

Value refers to the tangible and intangible benefits that the patients and community have gained due to the Glucose Trail intervention having taken place.

i) EDUCATION

Disseminating knowledge about this silent disease with phenomenal ramifications on longevity and quality of life, and with an opportunity to prevent diabetes complications through timely, effective intervention is very valuable. Health Care Companions trained in this pilot belonged to the communities they served, most being homemakers and they will continue to influence their own households and their extended social circles with the knowledge gained through this pilot. Patients themselves were motivated to take care of their disease understanding the complications that can occur and that these complications are preventable by getting their glucose to goal. Giving this silent disease voice by checking glucoses routinely, and educating HCC's and patients on glucose goals, BP goals, is a powerful self motivator. HCC's and patients learnt about the basics of a healthy diet, regular physical activity and taking medications as prescribed which are foundational for addressing chronic diseases.

ii) MONETARY VALUE

For HCC's: HCC's were trained pro-bono. In addition to their training, each HCC earned Rs. 4200 per patient through the course of the pilot. For example if an HCC oversaw 9 patients, she earned Rupees 37,800 through the course of the pilot. These stipends were designed to cover their logistical costs, not as a salary. Nevertheless it was the first time for many of these women to be given a leadership role in a professional context, and the reported a great self-esteem boost as well their family and peers viewing them with greater respect.

For Patients: A typical clinic visit to a diabetes specialist for a patient residing in PInd Begwal would incur the following estimated costs:

Transport cost Rs 1000+ time out of work ($\frac{1}{2}$ day of work estimated cost Rs 300) + doctor fee Rs 1000+ lab cost Rs 300 = Rs 2600 per visit.

Under the care of Glucose Trail, an average of 7 interventions were entered for patients in Pind Begwal. Given these estimated expenses, patients were afforded care worth Rs 18,200 each by the end of the pilot.

Each patient received diabetes expertise free of cost through the pilot. This happened four times as there were on average 4 interventions via the APP for each patient in Pind Begwal. Given a typical doctor's visit costs Rs. 1000 - Rs. 1500, they saved a total of Rs. 2000 - Rs. 3000. Given the intervention was remote they saved on time and transport costs, which typically cost Rs. 2000 for 2 excursions in a month to the nearest clinic. Lab costs were subsidised as patients were all tested at one time and location which led to a total cost saving of Rs. 155,750 for 989 labs. Most of all, given that on the whole the HBA1C's dropped on average for the patients compared how they would likely have fared without the intervention, cost savings on diabetes complications and personal productivity preserved would surmount any of these measurable costs during the course of the pilot.

iii) COMMUNITY EMPOWERMENT

One of the most valuable outcomes in this pilot was empowering community members. Despite academic qualifications, professional certifications, behavioural change within the community was only enabled through influencers from within the community. The success of the intervention in Pind Begwal occurred because of the presence of well intentioned influencers such as the Union Council. The status of the HCC's who were all women from Pind Begwal was raised over the course of the Pilot. By giving them education and tools to track and care for diabetes patients, their importance evolved within their households and the wider community. After 1 year of engaging with these HCC's, they have been given a gift that can keep giving back to their community. Patients themselves whose diabetes have improved will also continue to be a positive influence in their community and be a source of knowledge and inspiration within their community

iv) INCREASE IN HEALTH LITERACY

Health literacy is not limited to general knowledge about a particular disease. It encompasses the capacity of a patient to understand their disease, to know the services/ tools they need to treat their disease, treatment goals and how the disease can impact their functional capacity so they can plan ahead. This pilot injected health literacy in each community by teaching the HCC's and consequently the patients by disseminating basic diabetes knowledge, but also more detailed actionable information. This information included how to measure and goals for glucoses, ideal weight, ideal waist circumference and BP. Medication adherence is a very important concept that is not naturally understood. Through the pilot, emphasis was given to the type of medication, the dose and frequency of taking the medication, hence addressing this pivotal issue in treatment of chronic disease. The concept of measurable objective goals in determining efficacy of medication, rather than subjective symptoms which can often be misleading, is an important aspect of health literacy which was conveyed due to the design of this pilot. Most of all

health literacy enables a patient to advocate for appropriate care through their care providers and for themselves to make better choices in whatever is in their own control.

v) HARNESSING TECHNOLOGY

Using an APP to collect, track and analyse objective data to inform real time actions and future solutions was a valuable outcome of this pilot. For example, HBA1C reduction was fairly consistent in most patients under a particular HCC. Likewise, lack of HBA1C reduction was also consistent in most patients under a particular HCC. This data indicates at the potential impact of an effective HCC on patient outcomes. This objective feedback provides a basis to explore the difference in HCC practices. What made Zobina's patients do better than Noshia's patients? Noshia brought in 14 patients into the fold of Glucose Trail but what could she learn from Zobina in making her a more effective HCC?

Glucose data patterns and accurate entry of medications were also discernible in the APP indicating which HCC was more effective well before the final HBA1C tests results were available. This type of actionable feedback will be important in coaching HCC's in real time to improve upon the Glucose Trail Solution in future.

b) GROWTH

This refers to increase in capacity of the community and stakeholders involved in the intervention, that leads ultimately leads to long term benefit and impact.

i) CAPACITY TO EXPAND GT HEALTH CARE

Over the course of 1 year, 5 members of the Saving 9 team and 11 community members trained as health care companions and 1 endocrinologist were brought into the medical health care system, creating access to diabetes awareness and care to 83 patients in two low income communities. By bringing diagnostics to the community, the patients in Pind Begwal were evaluated anywhere between 15 to 30 times giving them objective feedback on their health status including labs by the mobile phlebotomist, finger-stick glucose checks, BP, weight and waist circumference measurements. Bringing these resources into the community is what enabled HBA1C improvements to occur.

ii) SPREAD OF DIABETES LITERACY

Over 150 individuals received diabetes knowledge over the course of this pilot. This knowledge was disseminated across two low income communities and in Islamabad including the Saving 9 team, health care companions and patients. Each participant may continue to be a source of knowledge in the communities in which they live, furthering the spread of diabetes literacy.

c) IMPACT

This refers to the bottom line improvement in direct medical outcomes for the patients that indicate that they have improved in their diabetic outlook.

i) IMPROVEMENT IN DIABETES CONTROL

There was an average decrease in HBA1C absolute value by -0.83 % in Pind Begwal and a 1.37 % increase in Bhara Kahu.

Challenges

The challenges to the project include getting initial buy-in for the GT model, as well as logistical and financial obstacles. These are elaborated on below:

i) TRUST AND LEGITIMACY

Gaining access into a community and being accepted as a trustworthy and capable source of care for a largely silent disease like diabetes is challenging. Not only does a community have to be convinced of the deleterious consequences of diabetes complications but that it is worth their while to engage in a healthy lifestyle and take medication/ insulin as prescribed and in so doing complications can be prevented. Alternative treatments especially to insulin and lifestyle change remains a major challenge in diabetes care. Insulin self administration and lifestyle intervention requires the patient to be the main participant in their own care. Alternative treatments that promise unrealistic outcomes will often distract or tempt patients away from foundational well grounded therapy. Glucose testing is the only objective way of verifying the effectiveness of any treatment, and if patients cannot afford meters/ strips or are unaware of glucose goals, effectiveness of treatment cannot be evaluated objectively.

ii) OPERATIONAL CHALLENGES

Diabetes and non-communicable diseases is a 'wicked problem' (Camillus, 2008). There are several ramifications of diabetes on physical health, mental well being, long term financial consequences, personal capacity and longevity. The solution to this medical disease is also multi-pronged. An ongoing prescription for diet, physical activity, tobacco cessation, oral medications, insulin therapy requires several resources, which need to be locally accessible, affordable and culturally acceptable. Adherence to each of these prescriptions is required to effectively manage diabetes in the long run. Operationally, an effective solution requires a well coordinated, collaborative team effort involving several stakeholders, the patient being the centre of the team.

iii) TECHNICAL CHALLENGES

Building an APP for low income communities that can be effectively deployed on affordable devices with offline capability are the technical demands for community outreach. The UI needs to be simple enough to

be used by non medical personnel but comprehensive enough to capture all the critical data needed to enable effective medical interventions.

iv) FINANCIAL SUSTAINABILITY

A life long chronic disease like diabetes ultimately needs to be managed by the patients themselves using affordable accessible resources. The solution needs to build on internal capacity to empower the individual and the community in which he/she lives rather than fostering dependency which would make the patient more vulnerable.

v) BEHAVIOUR CHANGE

The tobacco industry managed to flourish when cigarettes were made attractive through 'sexy' marketing, accessible by selling them in convenient locations and affordable. The demand was held steady as it is addictive and this industry took advantage of people's vulnerability. After several years of dedicated research during which the perils of tobacco use became apparent, the better informed and resourced areas of the world acknowledged its toxic effects. It took the persistent will and advocacy from the medical community, money and hard won government policy to fight this powerful industry and turn the tides of tobacco use. Now traditional tobacco use has waned in more informed/ resourced areas of the world. Its consumption remains high in less informed poorer areas of the world. These areas of the world do not have the advocacy or the governmental will or capability to fight this powerful industry and the likes of it (soda, processed foods, sedentary entertainment). The fight will have to come from the ground up rather than the top down.

The tough sell:

There is no easy demand for non-addictive substances. You have to create a demand for healthful items such as healthy foods, exercise items and reliable medication through education, information and advocacy on the part of health professionals. By prescribing diet, exercise, medications and insulin in a dedicated systematic way the demand can be created. The supply of these prescribed entities is just as important. If access or affordability comes in the way, the opportune moment is lost. From creating the demand to securing its supply has to be such a smooth process that people easily slip into the right direction.

Looking Ahead

Based on the positive outcomes and challenges that were observed during this pilot, the Glucose Trail is now considering several key changes to the way the intervention is adapted to the local context, and will use these in its next, larger scale pilot iteration. These are elaborated on below:

i) COLLABORATION WITH ABLE PARTNERS & GAINING ACCEPTANCE TO SCALE

Forging relationships with influencers within a community is key to engaging with a community. Glucose Trail is actively collaborating with Aga Khan University to gain access into already mobilised communities. Partnering with other non-profit organisations such as schools of Pehli Kiran is actively under consideration. Mera Maan is an important strategic partner who will enable us to gain access to communities such as Badbaan who are already mobilised through their own entrepreneurship initiatives. With a footprint in Pind Begwal we plan to build on our engagement with the community through Union Council. Glucose Trail, with Saving 9 is reaching out to academic institutions including Lakshmi Mittal and Family South Asia Institute at Harvard University, Teachers College at Columbia University and the Lahore University of Management Sciences to possibly partner on pilot projects. As the Glucose Trail Solution evolves through pilot projects, demonstrating effective medical outcomes and financial viability, engagement with governmental institutions is an important long term goal.

ii) SUSTAINABILITY AND EMPOWERING COMMUNITIES

There are a number of innovations under consideration:

- Negotiating a bulk rate for diagnostics, medication, insulin supplies, healthful foods (such as chakki atta), vegetables, rollator walkers, walking shoes etc could potentially subsidise costs increasing affordability and access to reliable diabetes products.
- Prescriptions for a healthy plate diet, regular exercise and medications will create a demand for healthful goods and services.
- By seeding social entrepreneurs through innovative approaches such as micro-financing, knowledge transfer and capital support, it will not only secure access and affordability of these prescribed products and services but will benefit community members, forming a strong eco-system within the community. Once the community has the opportunity to see the benefit of this approach, they will be the most effective marketing resource to expand the footprint within their own communities and to other communities.

iii) TECHNICAL INNOVATIONS

Glucose Trail is currently developing Version 2 of the Glucose Trail App. Improvements anticipated include an improved UI experience especially for the Health Care companion, off line capability, expanded interconnected persona in the APP including doctor, patient, health care companion, HCC admin, Pod manager. One of the most important structures being built into version 2 of the APP is tracking adherence to diet, exercise, medications and insulin in an objective measurable way. UI is evolving to be able to compare and track data at a glance to improve visibility and accountability for an individual patient, HCC performance and doctor performance.

iv) Summary of actions / pivots

Below is a table of actions or pivots we had to take to accommodate challenges encountered differing from planned or expected results.

Planned	Challenges	Action or Pivot	Result / learning																
Planned to recruit 50 patients at each community site in a time and cost efficient manner.	<p>Limited budget and time to market</p> <p>GlucoseTrail Diabetes Care solution and lack of trust as Glucose Trail was not a known entity in each community</p> <p>No funds were spent on general marketing.</p>	<p>First Recruited Health Care companions through a mobilized, trusted community through, the school in Pind Begwal (PB), then non- mobilized community through health Center in Bhara Kahu (BK). later still requested health care companions to personally invite/ convince their relatives/friends with diabetes to come</p>	<p>See Patient Camp Recruitment Table</p> <p>Recruitment Volume</p> <table border="1" data-bbox="1131 638 1425 842"> <tr> <td>1</td> <td>19/08/2018</td> <td>45</td> <td>PB</td> </tr> <tr> <td>2</td> <td>02/09/2018</td> <td>48</td> <td>BK</td> </tr> <tr> <td>3</td> <td>28/10/2018</td> <td>29</td> <td>PB</td> </tr> <tr> <td>4</td> <td>23/12/2018</td> <td>10</td> <td>BK</td> </tr> </table>	1	19/08/2018	45	PB	2	02/09/2018	48	BK	3	28/10/2018	29	PB	4	23/12/2018	10	BK
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4	23/12/2018	10	BK																
Planned to have a single baseline recruitment camp at a one location equidistant from both communities	Transport, time constraints and mobility were a barrier to members of both communities.	Recruitment camps were held in each location to surmount transport issues, and 2 recruitment camps were planned at each location	There was acceptable Attendance at recruitment camps																

<p>Planned to use local lab facilities at each recruitment camps to provide impetus for local businesses</p>	<p>No lab facility existed in Pind Begwal and reliable, affordable lab facility not identified in Bhara Kahu</p>	<p>Mera Maan advocated on behalf of both these communities and Islamabad diagnostics provided reliable diagnostics at a subsidized rate (which was covered by Glucose Trail), a mobile phlebotomist came to each recruitment camp</p>	<p>Glucose Trail learnt that advocating for vulnerable communities is a valuable function and businesses are more inclined to subsidize their product/ service if ordered in bulk</p>
<p>Planned to recruit patients efficiently at camps</p>	<p>Apathy in the community due to lack of knowledge about diabetes, its complications and significant benefits and getting glucose to goal</p>	<p>Provided labs free of cost and refreshments at each camp to convince community members to attend</p>	<p>There was acceptable Attendance at recruitment camps</p>
<p>Planned to do baseline lab tests on individuals with diabetes</p>	<p>Given this was an interventional pilot project, we budgeted lab tests for diabetes patients but because we provided labs free of cost, patients without diabetes also attended camps just to have their labs done for free</p>	<p>For third camp, individuals first had a fingerstick glucose to screen them for hyperglycemia or a prior history of diabetes was confirmed with review of medications/ prior labs before they had their baseline labs</p>	<p>The percentage of patients with HBA1C > 6.5 increased by the third camp. We also learned that subsidizing a service may prove more valuable than providing a service free of cost.</p>

<p>Planned to have patients bring all their medications to the recruitment camp</p>	<p>Despite HCC's requesting patients to bring their medications to recruitment camp, most did not.</p>	<p>Recording accurate medications each patient was taking was eventually accomplished through home visits or via whatsapp pictures. This expended valuable time, transport costs and effort.</p>	<p>Obtaining this critical information took much longer than expected. This experience informed us that there needs to be 2 camps in quick succession. A recruitment camp followed by an induction camp. At the recruitment camp, Glucose trail implementers need to clearly instruct all patients to bring their medications to induction camp.</p>
<p>Planned to invite local Grocers, local vegetable vendors, local Pharmacist to recruitment camp to facilitate connecting all the stakeholders creating a community of care</p>	<p>Lack of time and capacity left fostering these important connections undone</p>	<p>HCC's covered diet moderation, exercise and the importance of taking medications at focus group sessions with their respective patients</p>	<p>Fostering connections between a pharmacist, grocer, and recreational entrepreneurs within a community so that prescriptions for diet, exercise and medications can be locally sourced, hence creating a supply and demand within a community will remain an important goal of Glucose Trail</p>

<p>Planned to enter patient data directly into APP at recruitment camp</p>	<p>Lack of mobile connectivity, and personnel capacity and time, data could not be entered directly into APP at the recruitment camp</p>	<p>Data on all potential patients were recorded on paper at recruitment camps and later entered into Excel spreadsheets and into APP</p>	<p>Access to well organized and timely data by remote physician was delayed till all data was eventually entered into APP. A second induction camp would enable data collection on only confirmed diabetes patients, the APP should have the ability to work offline and the induction camp would require adequate staff/ volunteers to obtain and enter data into APP for immediate consumption</p>
<p>Planned to have each HCC interact with Glucose Trail APP on their personal 3G-4G mobile devices to enter their patients' data and review interventions via APP</p>	<p>The APP only worked online, data plans on HCC's personal devices were inconsistent, some content was not translated in Urdu and the APP was not fully functional at the commencement of the pilot and hence APP training was not a part of the initial HCC training session</p>	<p>Saving 9 staff initially entered data collected on paper into APP and then recruited an HCC ADMIN in each community who was tasked with collecting patient data from HCC's and entering the data into the APP.</p>	<p>This process impeded ready access to data, but an HCC Admin evolved as an important role to ensure accurate data entry into APP. The second version of the APP is being developed with offline capability, improvement in UX for better HCC usability. APP training needs to be methodically and comprehensively addressed in initial training sessions</p>

<p>Planned to have each HCC view interventions directly from the APP and convey instructions to patients</p>	<p>There was a lack of clarity if each HCC was conveying instructions completely and how long it would take before instructions were conveyed</p>	<p>HCC admins began to fill the important role of overseeing communication between HCCs and patients and Saving9 staff started arranging focus groups wherein they visited the community more frequently and could directly observe the interaction between the HCC and their patients</p>	<p>On appointing HCC admins and arranging focus groups, there was more completeness noted in data in APP, glucose levels began to trend down in some patients. The transfer of accurate, complete and objective information between the patient to the doctor and back to the patient is pivotal, requiring human interaction and technology. The APP and training is evolving.</p>
<p>Planned to have HCC's go with patient to pharmacy to help them purchase the prescribed medications at the correct dose</p>	<p>Limited logistics including coordination of time and transport and convincing patients to spend on diabetes medications allowed this to happen sporadically but not on a consistent basis. Some patients continued to lean on alternative remedies.</p>	<p>When patients stated they did not have enough money to pay for medications, Saving 9 organized community members to create a Zakat fund to help pay for poorer patients medications</p>	<p>Despite patients receiving diabetes expertise free of cost, all patients did not start taking medications as prescribed due to cost, apathy or using alternative remedies. Home glucoses remained high in these individuals and this was tracked in the APP. These objective outcomes are powerful feedback to promote adherence.</p>

<p>Planned to negotiate a discount for core diabetes medications through the community pharmacist</p>	<p>The pharmacist in Pind Begwal was very new and there was several pharmacies in Bhara Kahu. Saving9 was unable to negotiate these partnerships and Glucose Trail could not engage Pharmaceutical manufacturers for the small pilot</p>	<p>Patients obtained their own medications per instructions from HCC</p>	<p>Since obtaining medications prescribed was left to the patient, they started medications at variable times. If generic, core diabetes medications are sourced and subsidised through reliable pharmaceutical manufacturers for a community in a larger pilot, it can streamline patients actually taking prescribed medications on time</p>
<p>Planned to treat both communities through the entire duration of the pilot to compare outcomes between a semirural community Pind Begwal and a per-urban community Bhara Kahu.</p>	<p>HCC's in Bhara Kahu did not enter data in APP consistently and patients had not started medications prescribed through the APP. HCC Admin support was interrupted due to competing priorities, Bhara Kahu HCC's kept asking for higher stipends and demanded rental money to use their home to host any focus groups. Their participation was transactional and performance was inadequate.</p>	<p>By January 2019, Glucose Trail and Saving 9, decided to disengage with the Bhara Kahu. It was decided to test Bhara Kahu patients at the completion of the pilot and use this cohort of patients as a control group.</p>	<p>Working in a mobilized cohesive semi-rural community was easier. Saving9 had a prior relationship with Pind Begwal and forged a relationship with community leaders including the Union Council and the School which helped rally a more wholesome community spirit. Bhara Kahu, a more disjointed peri-urban locality with several alternative options will require much more engagement to muster a cohesive community effort</p>

<p>Planned to have a knowledge based questionnaire for patients at the recruitment camp and closing camp</p>	<p>There was not enough staff and time at recruitment camp to conduct questionnaires</p>	<p>Saving 9 recorded interviews with HCCs and some patients during the course of the pilot and conducted qualitative questionnaires to a few HCCs and patients at the conclusion of the pilot</p>	<p>Testing knowledge/ skill sets of HCCs at baseline, during the pilot and at 1 year in a structured, measured way is an important aspect of training and education which is evolving. Testing patients knowledge at baseline and after 1 year will measure impact and value of the HCC.</p>
<p>Planned to test all diabetes patients tested at baseline in both Pind Begwal and Bhara Kahu, at the completion of the pilot</p>	<p>Since HCC's in Bhara Kahu were not paid stipends to the end of the pilot, it was difficult to ensure patients would return for follow-up testing</p>	<p>Saving 9 collected all the mobile numbers of Bhara Kahu patients and explained to them that they will be contacted for follow-up blood tests in August of 2019 when HCCs in Bhara Kahu were terminated</p>	<p>Only 20 % of patients in Bara Kahu returned for 1 year follow-up testing. We learnt that to maintain a control group, HCC's still need to be employed to maintain contact with patients even if they are not actively educating/ supporting them</p>

Conclusion

It is clear from this pilot that the Glucose Trail model holds promise, and at the same time there were a lot of lessons learnt regarding how to refine the model and better adapt it for local context.

At the centre of the intervention is the relationship that is fostered between the HCC and his/her patients. Behaviour change, that is so important to preventing early stage diabetes, requires an effective combination of emotional connection and sound medical intervention. Perhaps HCC Noshia was not effective in Pind Begwal, after accounting for potential work ethics challenges, because the number of patients she had to foster such a bond with was very demanding. Just like how in the field of education the student:teacher ratio is a significant metric that plays a role in determining the quality of the classroom, the HCC:patient ratio is a similar metric to keep in mind for the next pilot. The focus groups further illustrate this point about patient psychology playing a key role. These group meetings fostered more direct connections between patients of the same HCC (who happen to in many cases be family relatives as well), and this helped the patients see their HCC's in a new light as community leaders. It also helped the patients feel that they were in this alone, and there were some powerful moments when for example some patients confessed during these group discussions that they actually did consume tobacco.

Other key lessons and hunches validated include the potential of the APP, and the need for encouraging solutions from the community itself. The APP helped provide a convenient interface for the remote diabetes specialist to process the patient data, but at the same time there were challenges with the quality of entry of the data. Upcoming Version 2 of the APP will incorporate these lessons, and produce a more comprehensive and user-friendly product that is tailored to the needs and capacities of the different stakeholders who will be connected through it. There were challenges that the HCC's and patients expressed at various points throughout the pilot such as raising funds for the purchase of medicines for the particularly financially challenged patients. It took a while to change the mindset that support will be given to them from the 'outsiders' who initiated this intervention in the community. But it was encouraging to see that they then worked towards solutions such as financial pooling and availing zakat funds for this purpose.

The pilot shows that there is promise in the Glucose Trail model because on average the HBA1C's improved compared to the pseudo-control group in Bhara Kahu. It is important to now study how this intervention will fair after incorporating the lesson from this first pilot, and from an increase in scale. We encourage others to learn from this pilot, and to take part in this effort to foster sustainable community-based solutions to the 'silent killer' and 'wicked problem' that is diabetes.

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