Deficiency, inventory

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Abstract

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Type 1 diabetes is a condition primarily characterized by complete insulin deficiency. The pancreatic beta-cells lose their ability to help regulate the level of glucose in the bloodstream. This work follows a line of inquiry looking at life with a chronic health condition as a practice. Tracing the condition from onset to management, general knowledge, and history, it began as research into layers of lived experience; over time building a catalogue of tools, materials, and ritual, and ultimately organizing a new inventory of perspective from which to draw a map.

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Introduction

Type 1 diabetes is a condition primarily characterized by complete insulin deficiency. The pancreatic beta-cells lose their ability to help regulate the level of glucose in the bloodstream. This work follows a line of inquiry looking at life with a chronic health condition as a practice. Tracing the condition from onset to management, general knowledge, and history, it began as research into layers of lived experience; over time building a catalogue of tools, materials, and ritual, and ultimately organizing an altogether new inventory of perspective from which to draw a map.

Background

This project deals with type 1 diabetes, an autoimmune disorder which results in the body being unable to regulate the level of glucose in the bloodstream. The process of a person with diabetes to regulate this level takes two forms of correction: insulin is required to lower the level of glucose, and carbohydrates or food are needed to bring it up. While therapies and treatments continue to improve, there is currently no cure. The cycle of correction is ongoing. While I have had diabetes since the age of six, I never thought about seeing beyond the day to day maintenance, which can be significant work. With an opportunity to look more closely, I wanted to learn how to talk about it, to learn more about what it is, where it comes from, and what I might share in common with others living with the condition.

In June of 2018 I started a new project. The insulin pump I was using was no longer under warranty, and so I became eligible for an upgraded device. This happens every four years or so. Most insurance companies will be able to offset the cost of the replacement device—which runs into the several thousands of dollars—with a copay. Looking into what might be available, and what new features they might offer, I learned about an alternative: an emerging movement of people who had figured out how to exploit a security loophole in a much older pump in order to control the delivery of insulin based on data coming from the sensor of a continuous glucose monitor. The algorithm was developed by a small group of real-world n=1 test subjects for the same small group of real-world n=1 test subjects. The developers were all living with type 1 diabetes, or indirectly affected by the condition. The group was documenting and distributing this information to the public, encouraging others to teach themselves and join in. The project, created and led by Dana Lewis (person with diabetes) and her partner Scott Leibrand (partner of a person with diabetes), is called 'OpenAPS', the first open-source artificial pancreas system.[1] I was moved as much by the ingenuity and persistence of the development as the public solidarity and close-knit dialogue of the community. As I was considering whether or not to give this a try, I

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[1] See OpenAPS.org for full documentation of this project. The website is remarkable for its thorough explanation and its inventory of knowledge, and its commitment to free distribution.

remember speaking with my endocrinologist, who was nice enough to take some time on the weekend for a call to discuss what it might mean to use a system like this. While he was not allowed to prescribe the system to me—I initiated the conversation—he encouraged me to look into all available possibilities and would offer support as best he could for whatever decision I made. Diabetes is a work-in-progress, after all. The doctor believed the type of people who were doing well on this system were those paying particular attention to their condition, and who were particularly motivated.[2] I understood this as a caution, and in retrospect I wonder if it wasn't also a challenge. By the end of the conversation I felt comfortable with the idea of tracking down the components to give it a try. I remember at the very end of the call saying, "I'm not sure I want to turn my life into a science experiment…" He seemed to pause to laugh. This pause stuck with me. It occurred to me later that my entire life as a person with diabetes had long-been a science experiment.

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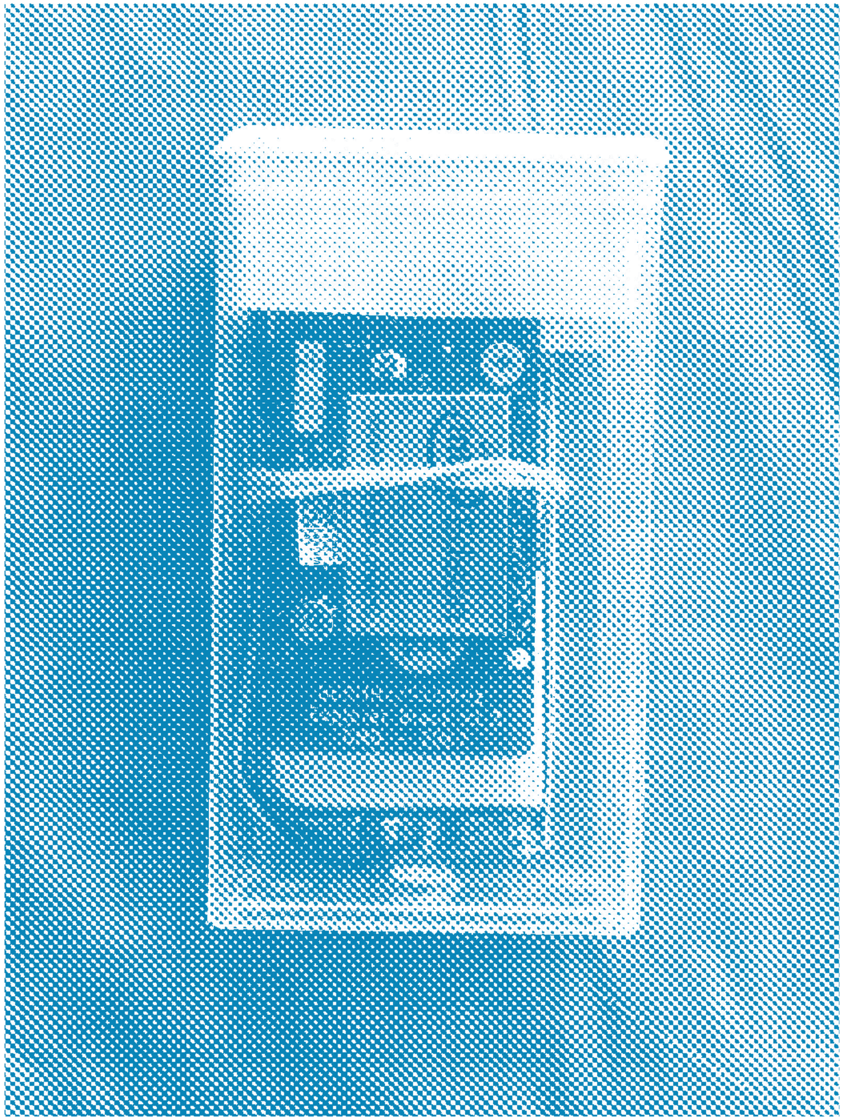
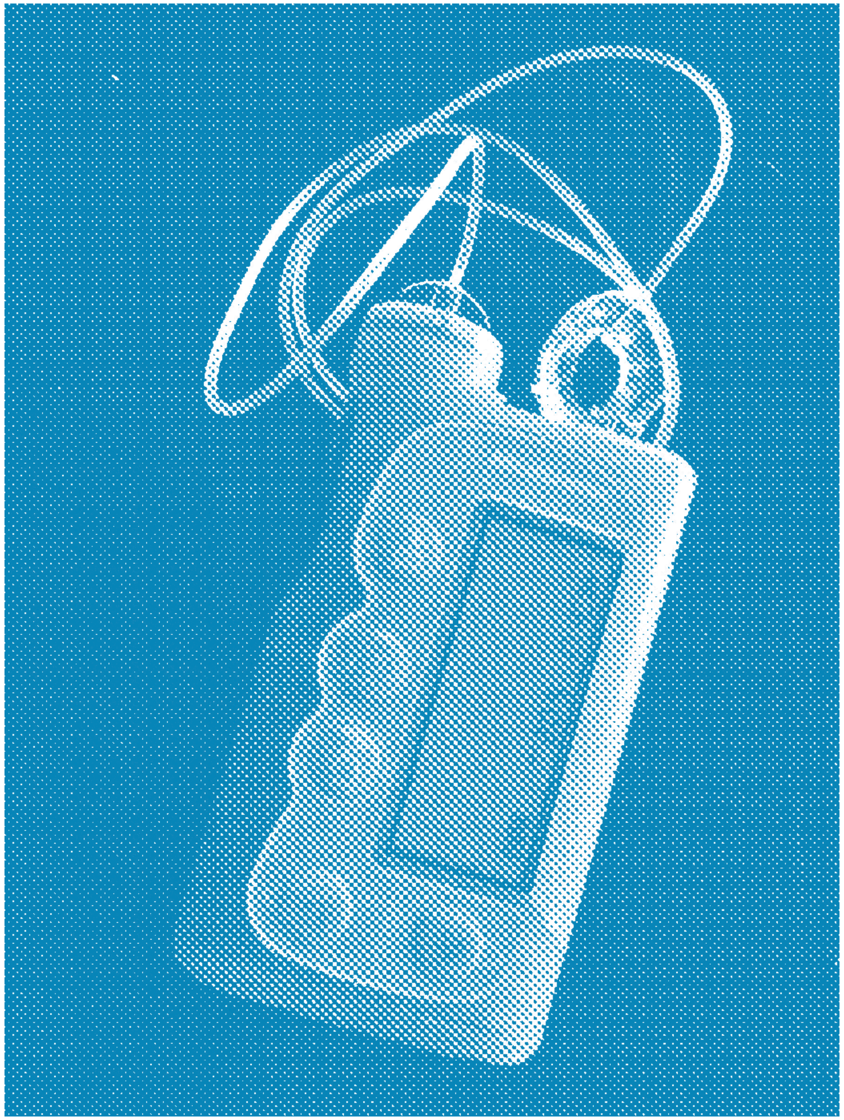
[2] It goes without saying that people who are manipulating medical devices to improve their health are showing particular motivation. However, it is important to recognize that the technology is not plug-and-play, and adding the weight of more tasks by taking on new burdens can increase the risk for burnout.



The OpenAPS rig.



Medtronic 722 insulin pump (pink).

Later that summer I would travel to Arnhem, NL, for a design workshop. When packing my suitcase, I realized that a significant amount of space was dedicated to diabetes supplies: cartridges, infusion sets, continuous glucose monitoring (CGM) sets, glucose tablets, etc. I knew I would have a roommate and wondered what this person might think when seeing all of this. I had never needed to explain these things, they are always hidden from sight. I rarely talked about diabetes with anyone. Would they be affected by these things? Would they be interested? Maybe they wouldn't care at all.[3]

The workshop, coordinated by designer and ArtEZ University Graphic Design program director Thomas Castro, centered on the process of exploring and developing one's own methodology.[4] Visiting designers and theorists offered independent perspectives through studio talks and visiting critiques. My research in Arnhem dealt with the nature of the various materials used on a day-to-day basis as a person with diabetes, alongside the fact that they remain reliably hidden from sight almost all of the time. Considering the small size of all of the components, the first step involved enlarging each of these materials to poster-scale, and flattening them in monochrome-red prints to cover

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[3] Roommate is a great person, this was never an issue. Hi JP!

[4] GDA Summer Sessions, a two-week intensive workshop at the ArtEZ academy in Arnhem. Tutors included Coralie Vogelaar, Danny van der Kleij, Donna Verheijden, Jeremy Jansen, Joris Maltha, Remco van Bladel, Simone Trum, and Thomas Castro.

the wall.[5] Next, arranging a display of the original pieces on a platform in front of the wall. The bottle, cartridge, pump, battery, sensor, insertion device, etc.—numbered, ordered, and set for viewing, each with a small label showing the manufacturer and product name.[6] This display offered me an opportunity to speak candidly about the lived experience of a person with type 1 diabetes for the first time—discussing stories and conditions around these materials typically kept private—with a group of complete strangers. Alongside the material display showing the tools and objects themselves was a short fill-in-the-blank form. The form describes the daily rituals of a person with type 1 diabetes, the repeated process and reflection. In setting up an inquiry into the tools and rituals of everyday life, it became clear that life with this condition is, itself, a practice with its own methods.

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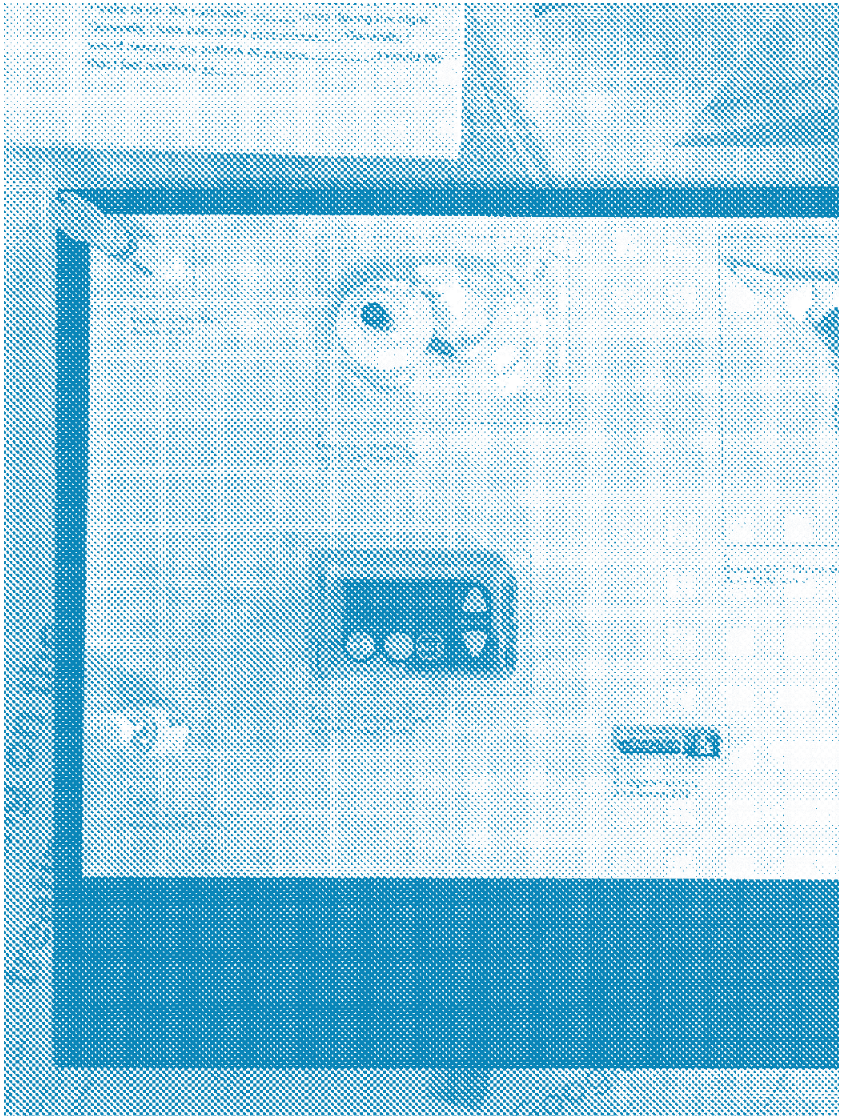
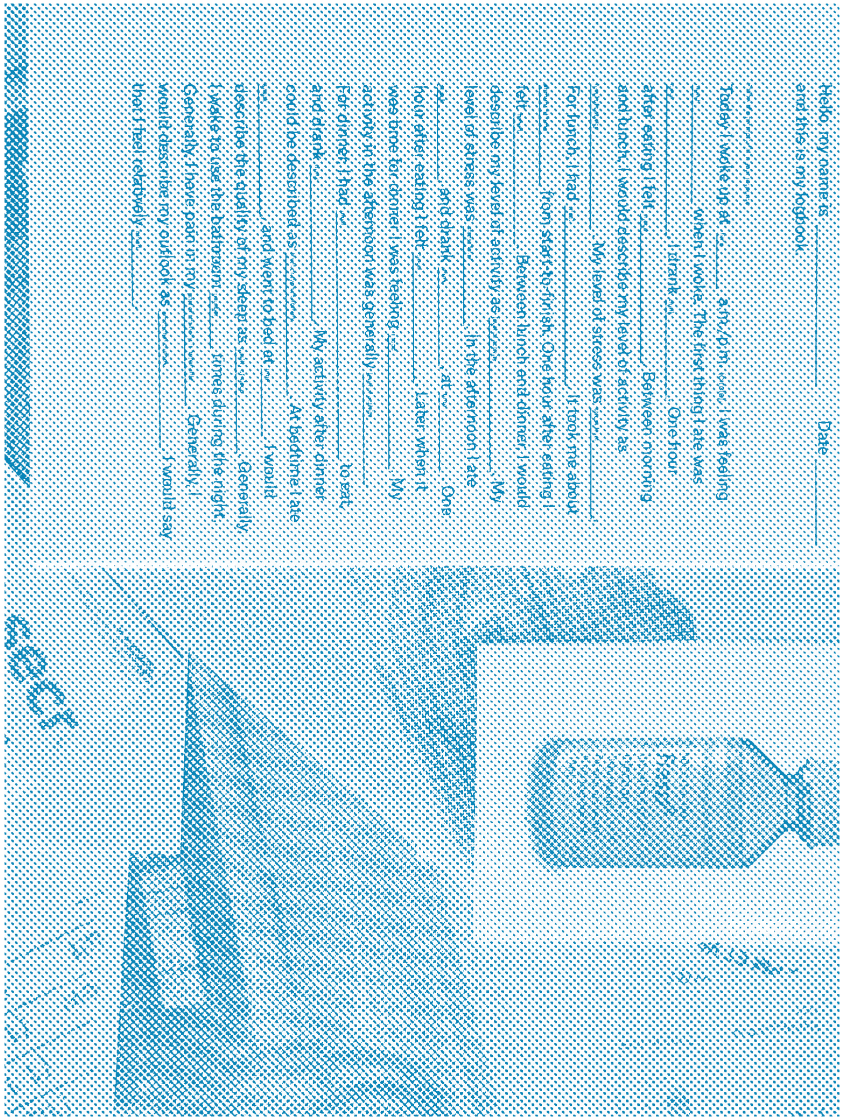
[5] Simone Trum suggested that I use the school's printers and begin to work at a larger scale.

[6] Display of the actual components grew out of a conversation with Coralie Vogelaar about the material qualities of one of these objects which I had with me in studio that day—a bottle of insulin.

Display of process work at Arnhem.



Display of process work at Arnhem.

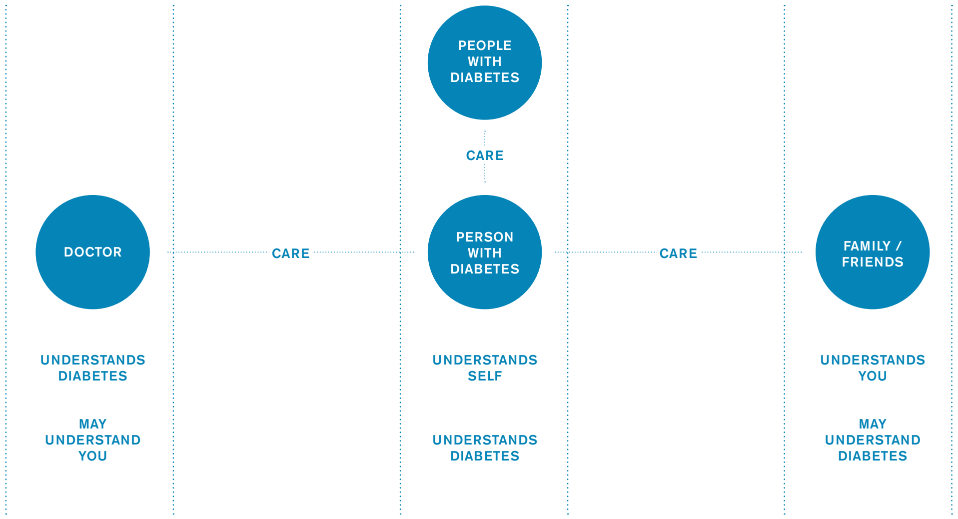


Hello, my name is ____________ Date ________
and this is my logbook.

Today I woke up at ______ a.m./p.m. I was feeling
____________ when I woke. The first thing I ate was
______________. I drank ____________. One hour
after eating I felt ______________. Between morning
and lunch, I would describe my level of activity as
______________. My level of stress was ____________.
For lunch, I had ______________. It took me about
__________ from start-to-finish. One hour after eating I
felt ____________. Between lunch and dinner, I would
describe my level of activity as ______________. My
level of stress was __________. In the afternoon I ate
__________, and drank __________, at ________. One
hour after eating I felt ____________. Later, when it
was time for dinner I was feeling ____________. My
activity in the afternoon was generally ____________.
For dinner, I had ______________ to eat,
and drank ____________. My activity after dinner
could be described as ____________. At bedtime I ate
____________, and went to bed at ________. I would
describe the quality of my sleep as __________. Generally,
I wake to use the bathroom ______ times during the night.
Generally, I have pain in my ____________. Generally, I
would describe my outlook as ____________. I would say
that I feel relatively ________.

Display of process work at Arnhem.

Wall of research materials in Arnhem, charting the map.



Network of care

Thinking about the experience of a person with type 1 diabetes, I diagrammed a series of columns. At the point of diagnosis, it is isolating. And yet, there may be some balance provided by a few different people, or groups of people. If you are lucky then you have a doctor who understands diabetes, and may over time understand you. On the other side, you may have family or friends who understand you, but do not understand diabetes. They may even misunderstand the condition. Between these two is a column which is often not sought out: people with diabetes, who understand the experience directly. This diagram is one way to articulate both differences and similarities between three columns in a network of care.[7]

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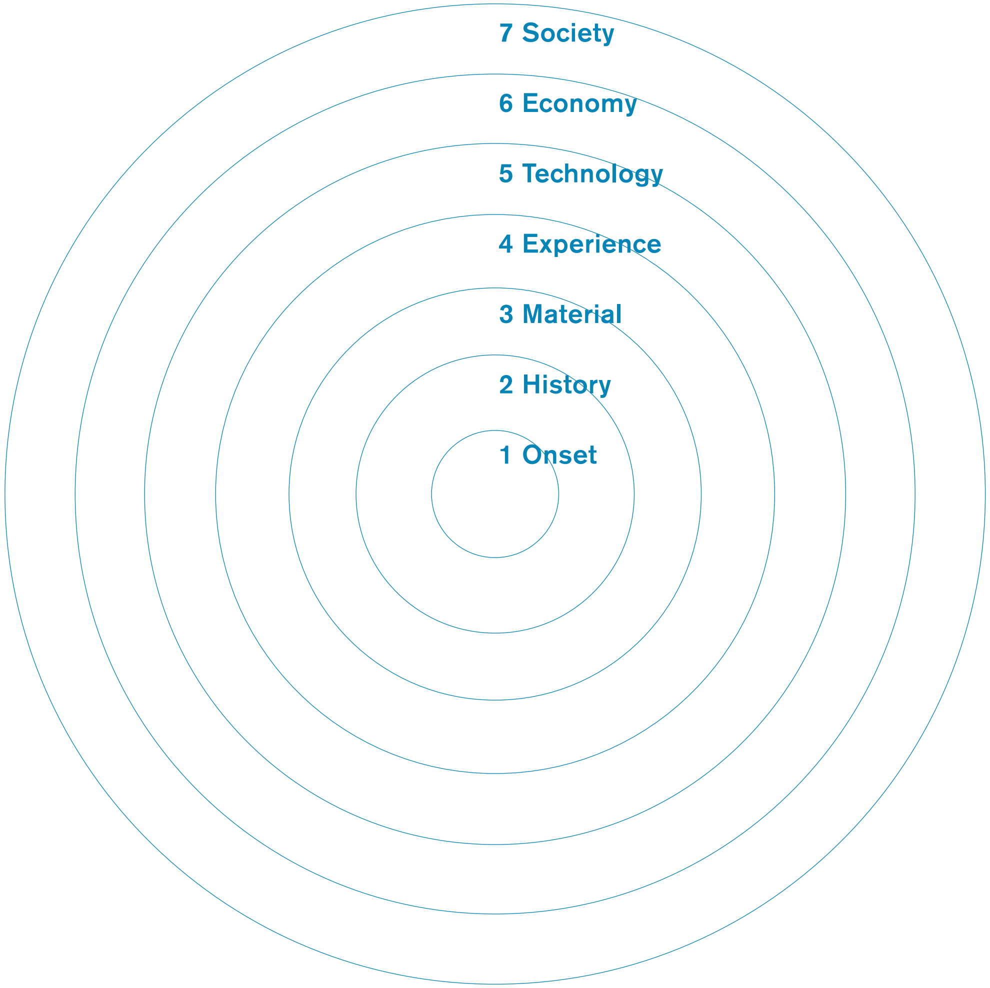
[7] It could be that someone at some point has explained diabetes to me in this way, because it seems too clear to be of my own thinking, and if it's the case, I give credit to whomever it was, but I cannot place it specifically. Here is a diagram of the concept.



Back in Seattle in the fall I was encouraged to expand this work and consider the landscape or layers of experience of a person with diabetes more broadly. My first attempt to chart this was moving from the center of the experience—from the cellular level outward. The condition begins at *onset* (1) when the body realizes something is out of the ordinary. A mystery at many levels, the root causes of type 1 diabetes remain unknown. However, there is a long *history* (2) of diagnosis and life with the condition. Looking at this history today is reassuring—even humbling—to see both that life is improving over time for a large number of people, and that many in the past have been committed to making life better for those living in the present. Looking into the visual history reveals connections to iconography. For example, I learned that the Egyptian figure of the Apis bull has been used as the logo for Novo Nordisk, one of the largest producers of insulin (which I use) since 1925.[8] A look at the *material* (3) and the *experience* (4) was initiated in Arnhem: the tools and rituals of life with type 1 diabetes as a practice in the present, from more sophisticated supplies to basic Haribo bears sometimes used to correct lows. The project starting with OpenAPS speaks to the emergence of new *technology* (5)—thinking about the future—created in direct counter-dialogue with the status quo of current diabetes e*conomy* (6), with knowledge and materials being developed

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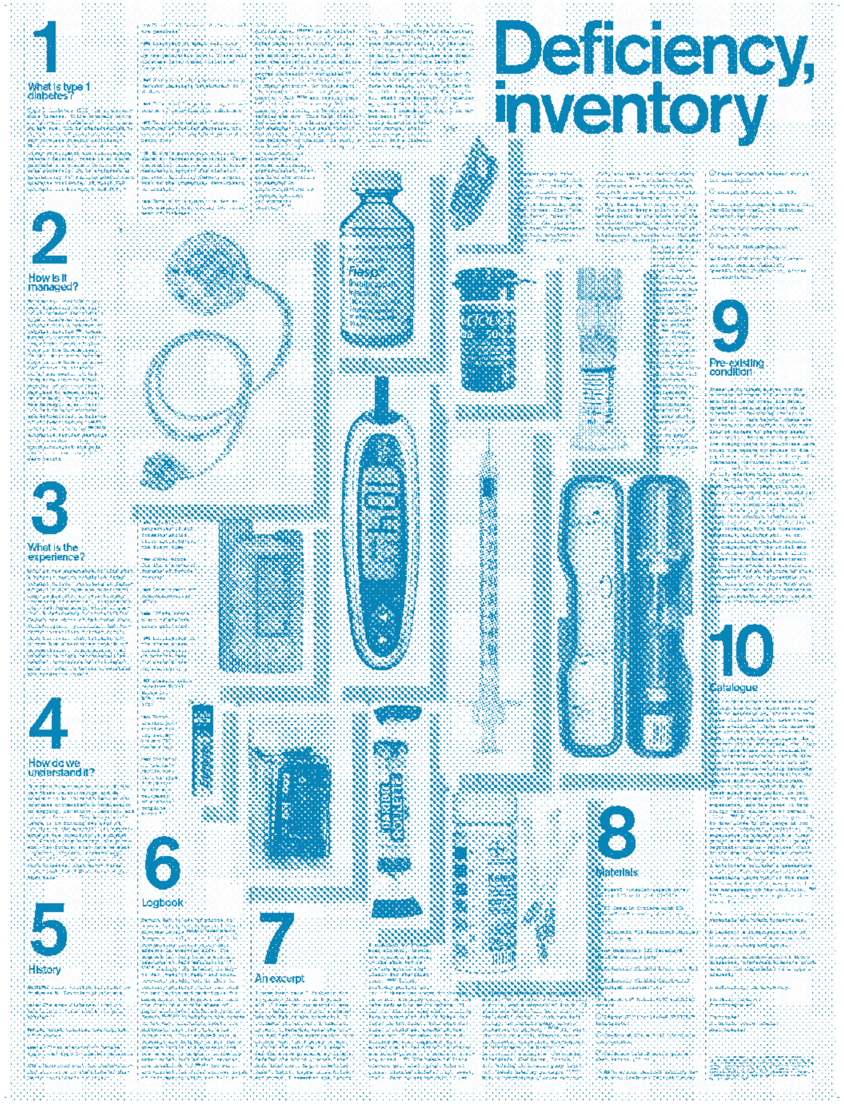
[8] See Novo Nordisk, 'Our Logo': https://www.novonordisk.com/about-novo-nordisk/facts-and-figures/our-logo.html



Broadsheet and attempt to merge the materials with layers of experience.

from the ground up, from the side of people living with diabetes, and is given away for free. At the same time, these conversations inevitably affect public perception of people with diabetes in politics and life in *society* (7), from everyday encounters to political debates over access to tools and information.

The first printed piece to place the materials from the Arnhem work in the center of these levels of engagement was a broadsheet. The materials, numbered, are cross-referenced in the text, serving as a connecting thread between the layers of experience moving outward. The layers are also ordered, beginning with four questions: ‘What is type 1 diabetes?’, ‘How is it managed?’, ‘What is the experience?’ and ‘How do we understand it?’. The following sections provide more subjective assessments of the history, logbook (data), an excerpt (memory), materials (tools), and pre-existing condition (perception). The final section is a summary and proposal for a catalogue of these layers.

At this point in the project the work remains focused on the materials. At the center of the broadsheet and cross-referenced throughout the text, are the materials that a person with type 1 diabetes depends on, which hold the ground in concept and in form. With the new text, however, the work also begins to transition from a simple display to an informative resource.

At this point in the process I felt lucky to be in Seattle, Washington, where a few important people happened to be at the same time. It is likely that I would never have been motivated to start this project, or thought this topic worth looking into, had I not met Dana Lewis (person with type 1 diabetes, co-creator of OpenAPS), Dr. Irl Hirsch (person with type 1 diabetes, endocrinologist at the University of Washington), and Thacher Hussain (person with type 1 diabetes, patient advocate, now working with Tidepool).[9] Meeting people who share lived experience and find unique ways to engage with the condition and offer their knowledge and encouragement to others has been an immense source of inspiration in this process.

Taking the inquiry further, I traveled to the 32nd annual Advanced Technologies & Treatments for Diabetes (ATTD) conference in Berlin. It was reassuring to run into Dr. Hirsch at his talk. It was also motivating to see an entire session dedicated to the open-source and DIY APS systems in which the work of Dana Lewis and others was put in dialogue with the most advanced scientific research available.[10] It was enlightening to discover the huge number of people who are dedicated to the project of improving the lives of people with type 1

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[9] 'Tidepool is a nonprofit organization dedicated to making diabetes data more accessible, actionable, and meaningful for people with diabetes, their care teams, and researchers.' From their website. For more information, see tidepool.org.

[10] Panel, 'Do it yourself in diabetes' with Dr. Katarina Braune, Dr. Lenka Petruzelkova, and Daniel Finan. Saturday, February 23, 2019. ATTD 2019, Berlin.

diabetes. The conference was educational as it encompassed not only the diversity of presentations from researchers, but the commercial companies producing the materials from the early stages of the work. It was encouraging to see these sides working together.

One month later I attended the Children with Diabetes *Friends for Life* conference in Seattle.[11] While there were scientific sessions including a few of the same researchers from Berlin, the focus of the gathering was on families, particularly those newly diagnosed. On the tails of returning from a conference in which nearly everyone was an expert on some component of the field, speaking over coffee breaks and during lunch with children and parents on the threshold of a totally unknown experience provided a significant contrast. My concept of this community grew significantly at these conferences. Somewhere between these two groups I felt realigned in a moment where I knew that I had both something to share and still so much to learn. From these experiences I can share the following:

People with diabetes share a second language. In this experience—many from a young age—we learn to speak the same language; a mix of science, technology, emotion, physical feeling, and wit.

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[11] ‘Children with Diabetes focuses on care today, so we are ready for a cure tomorrow. As an advocate and global resource, we provide support, education and inspiration to empower families and all people living with diabetes to enjoy healthy, enriched lives.’ from http://www.childrenwithdiabetes.com/about-us

People with diabetes have not always shared their experience. An ADA-listed disability, people with diabetes have been discriminated against in popular media and in the workplace.[12] We have gained rights and respect over time. Some with the condition continue to hide it.

Your diabetes may vary.[13] A common refrain in the diabetes online community. Millions are connected through the fundamental burden of life with type 1 diabetes. Each is a unique participant-observer with unique methods of therapy. There are guidelines, but there is no one ‘right’ way.

Participation makes a difference. Whether online or face to face, making contact with the community expands dialogue. Participation takes many forms.

Diabetes is a work in progress. Small changes can make big differences. A unit too much and in twenty minutes you may be in hypoglycemia. A unit too little and you may become ill. It is a process-oriented practice, with trial and error, wait and see. Incremental analysis, reflection, and changes over time are expected.[14]

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[12] Type 1 diabetes has been listed by the Americans With Disablilites Act since 2009. See, https://adata.org/learn-about-ada

[13] I learned of this term through its emergence in the Diabetes Online Community as a hashtag on social media, #YDMV.

[14] I was reminded of this at the CWD FFL conference in Seattle when listening to Dr. Bruce Buckingham discuss the history of diabetes technology. Describing the course of research and development he paused to say: “And what is diabetes, if not trial-and-error?”

A ‘new’ inventory

At this point in the project I felt motivated by the process. Meeting many new people and learning about life with a chronic health condition amongst those with shared experience helped me to better understand my own.

While I had become more comfortable with the process of publicly discussing my diabetes with others who share that experience, it was a challenge to imagine what forms that might take with a broader audience.

I began to explore a new inventory through forms that were familiar to me as a book designer. I referred to small-press publishers I looked up to: Winfried Heininger (Kodoji), Harsh Patel (Sister), David Reinfurt and Stuart Bertolotti-Bailey (Dexter Sinister) and Roger Willems (Roma), and work I had just seen in the Netherlands by artists and designers Jeremy Janssen, Sandra Kassenaar, Coralie Vogelaar, and Simone Trum and Loes van Esch (Team Thursday). I wanted to make work in this spirit to expand my thinking about ways to process this research.[15] To start, my goal was to abstract the layers of experience, making printed material with topics charted through diabetes research. As studies, each new part of the catalogue became process pieces. I hoped that what emerged would help me to articulate the condition further, at least for myself, to be able to see it in a new way.

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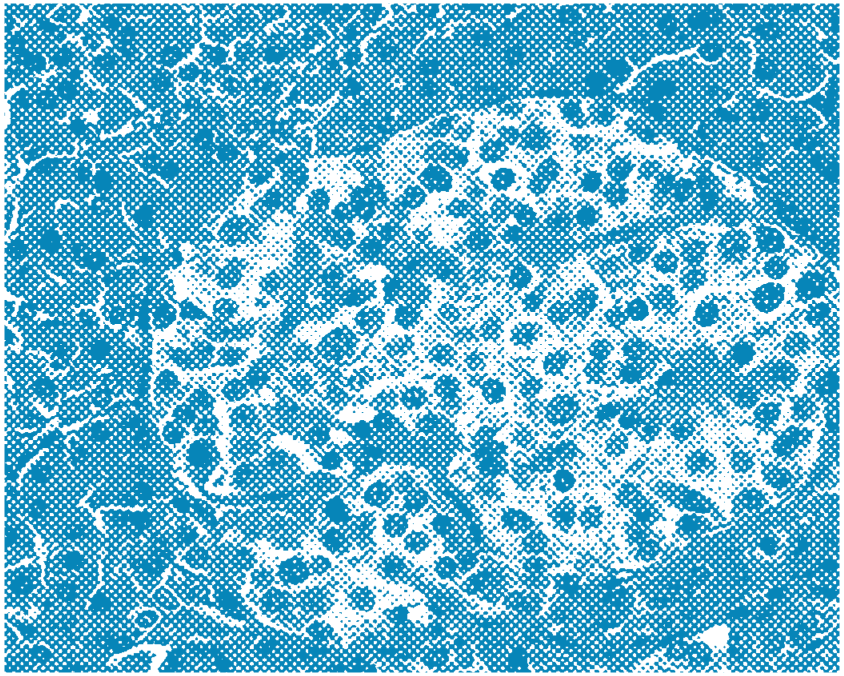
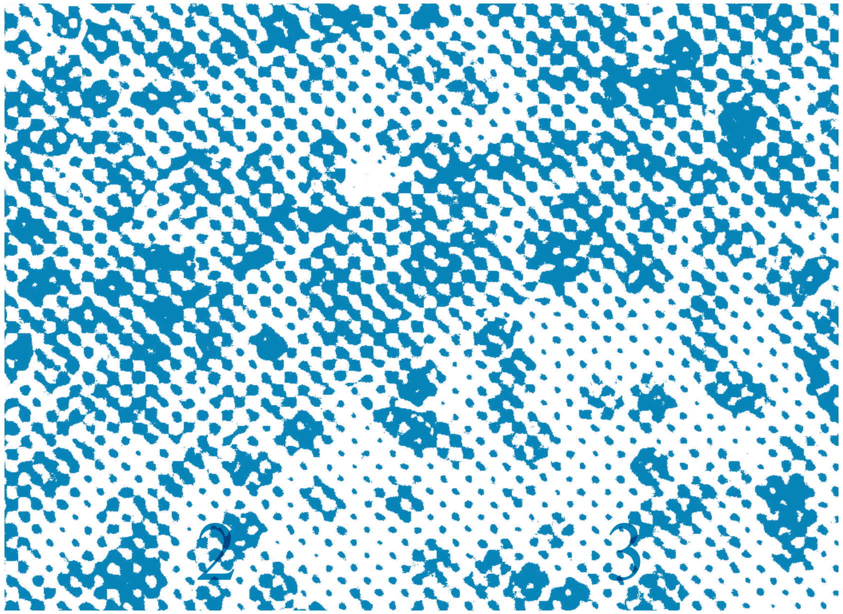
15 Looking back, the basis of this approach was motivated by my insecurities as a designer, afraid to trust myself. I didn’t realize it at the time, but by the end would better understand a feeling I had in Arnhem that I took for granted then: the form’s connection to the content and process is what makes all of these practices distinct and admirable.



1. Onset

Diabetes begins at the cellular level, at a scale so small you can only see it with a microscope. The rippling effects are greater, beyond the individual and out to a larger system. Images of the beta-cells in the pancreas resemble a halftone printing pattern. Up close, you can be told where you are, and what is happening, but it's not clear what is happening, or why. The feeling is persistent. Similarly, after living with type 1 diabetes for some time it can be difficult to re-examine one's relationship with the condition, and with its practice: when you are so close to something, it can be difficult to see it. This seemed like a starting point from which to work outward.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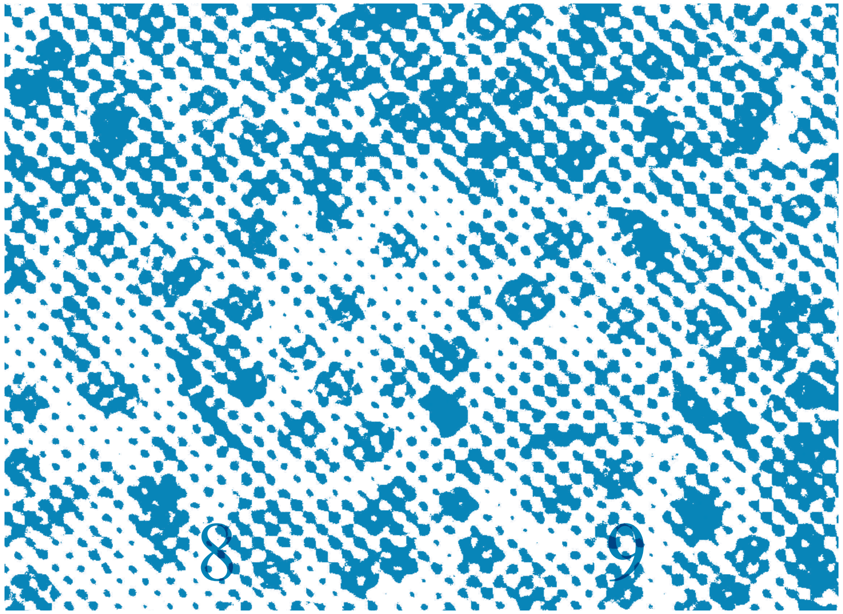
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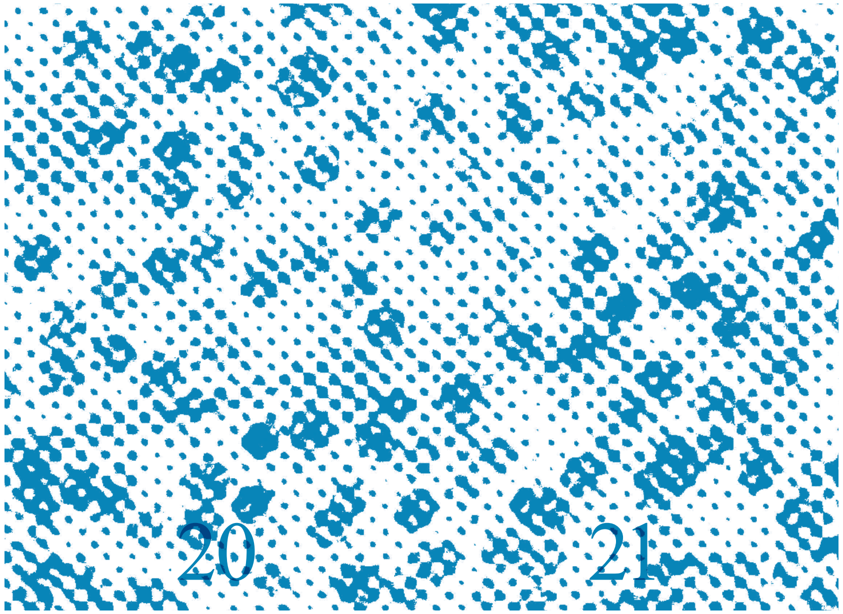
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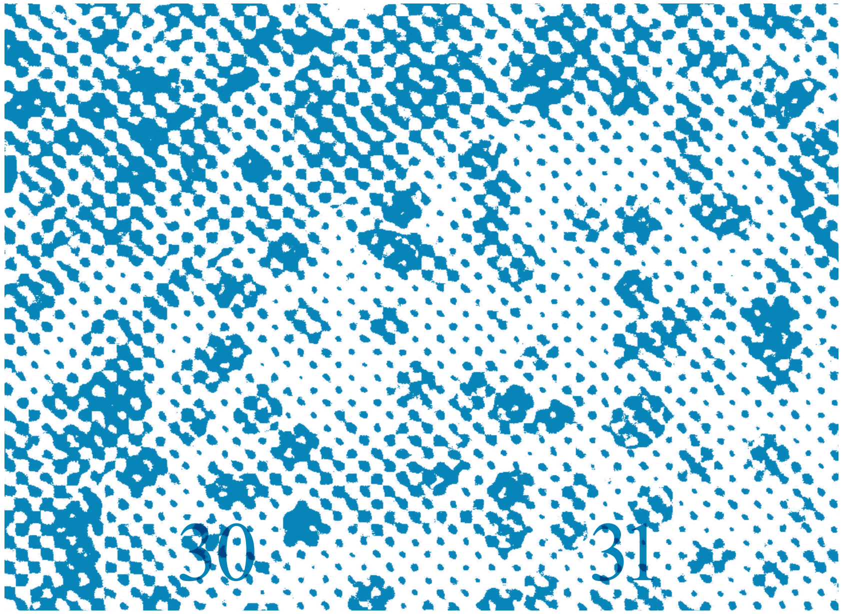
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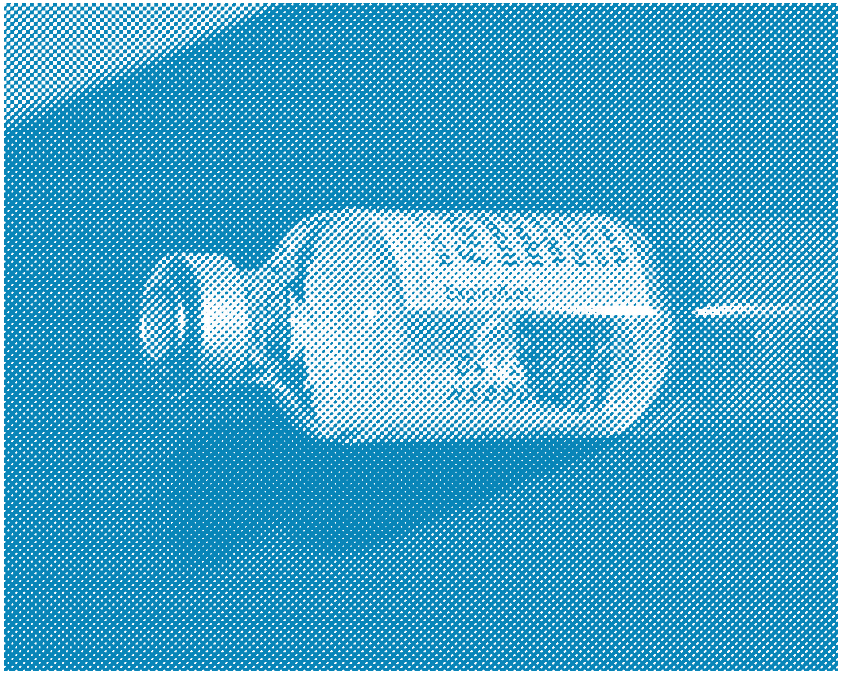
$$\frac{BG - (100)}{x}$$

1u per x g (CHO)

70 – 180

2. How-to

Diabetes is complicated, but it was once the case following diagnosis that you were given only a limited amount of information: a correction factor, mealtime dose, and control range for blood-glucose levels. This is a reminder of the earliest education received when diagnosed with type 1 diabetes, and an introduction to the first steps of a language spoken by people with diabetes. On diagnosis, one was once given this information, a prescription for insulin at the pharmacy, some glucose tablets, and sent out the door. Today education programs are improving and information is more available and widely distributed.



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6:16p

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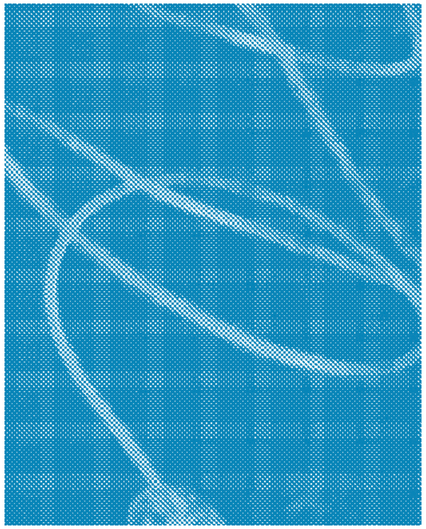
3. Everyday

Over time, the tools and rituals of managing the condition become mundane, part of one's everyday experience. It can be easy to forget they are in any way out of the ordinary, and after many years these things can be taken for granted. Meanwhile, the constant measurement and logging of blood glucose levels, like a kind of timestamp, is always present.



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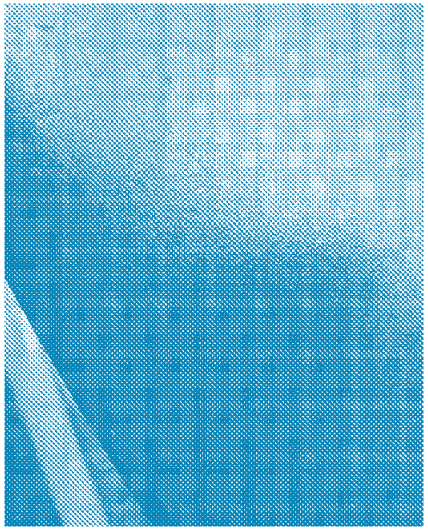

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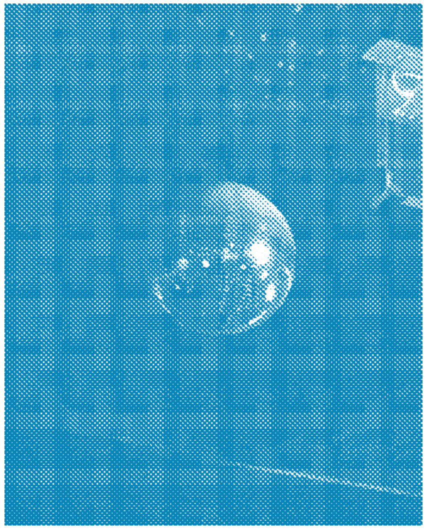

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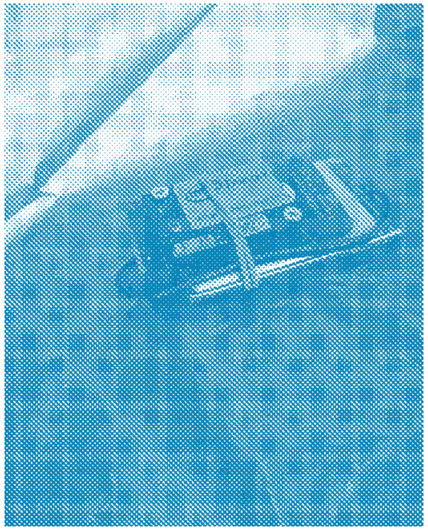

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Deficiency, inventory
Lexicon

4. Lexicon

People with diabetes speak a second language that is both formal and colloquial. Yet it exists as a mostly-spoken language for anyone who isn’t a specialist. For someone without this lived experience, it can be difficult to appreciate the volume and breadth of terminology that becomes commonplace around the condition.

in the blood and is the main sugar that the body manufactures. The body makes glucose from all three elements of food—protein, fats, and carbohydrates—the largest amount of glucose derives from carbohydrates. Glucose serves as the major source of energy for living cells. However, cells cannot use glucose without the help of insulin.<?>

Glucose Gel

A gel made of glucose which typically has 15g of carbohydrate and 15g of glucose in a single serving. The gel is designed specifically to treat hypoglycemia for regular measure and fast absorption. In particular, they can be administered by another person in the event of hypoglycemic unconsciousness. They are made by a number of brands and come in a variety of flavors.

Glucose Tablet

A large, chewable, candy-like pill made of glucose which typically has 5g of carbohydrate and 5g of glucose. The tablet is designed specifically to treat hypoglycemia for regular measure and fast absorption. They are made by a number of brands and come in a variety of flavors.

Glycemic Variability (GV)

A metric used in describing the range of variation in the level of glucose in the bloodstream over a given period of time. Higher GV in the short term can give feelings of sickness, while in the long-term can contribute to oxidative stress and complications. The measurement is important, as while an A1C number at or below 7% may indicate good control, it is only an average. GV shows the quality of control over time.

GlycoMark (AG 1,5)

An indicator of glycosuria. When blood glucose is well-controlled, glucose and 1,5-AG circulate in the bloodstream. The molecules are filtered by the kidneys and reabsorbed by the body. Urinary 1,5-AG is equal to the ingested 1,5-AG. When glucose exceeds the renal threshold (>180 mg/dL), glycosuria blocks reabsorption of 1,5-AG. 1,5-AG is excreted in the urine resulting in lower 1,5-AG levels. The GlycoMark test measures 1,5-AG from a serum or EDTA plasma blood sample.<?>

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Hemoglobin A1c

A blood test which results in a number representing three months of glucose values on aggregate. The number is measured against a chart to standardize levels of blood glucose control. For decades it has been the standard value by which people with diabetes and their doctors have both measured and been measured by. Standard of care suggests a regular A1c of 7% or lower (average BG of 136–162) results in significantly better outcomes and fewer complications. With the emergent possibility for higher-resolution data and greater knowledge about glucose exposure in the bloodstream, this standard is being supplemented by other measures such as Time in Range (TiR), Glycemic Variability (GV) and Coefficient of Variation (CV).

High-deductible plan

In the United States, a high-deductible health plan is a health insurance plan with lower premiums and higher deductibles than a traditional health plan. Being covered by an HDHP is also a requirement for having a health savings account.<?>

Hybrid Closed Loop (HCL)

In the context of the insulin pump, a hybrid-closed-loop (HCL) system is partially automated with a control algorithm coordinating insulin delivery data from the pump and glucose data from a continuous glucose monitor (CGM). In the HCL system, variability of glucose in the bloodstream is actively managed by a fluctuating basal rate calculated by the algorithm. Most if not all mealtime and some correction boluses are administered by the user manually.

High-risk pool

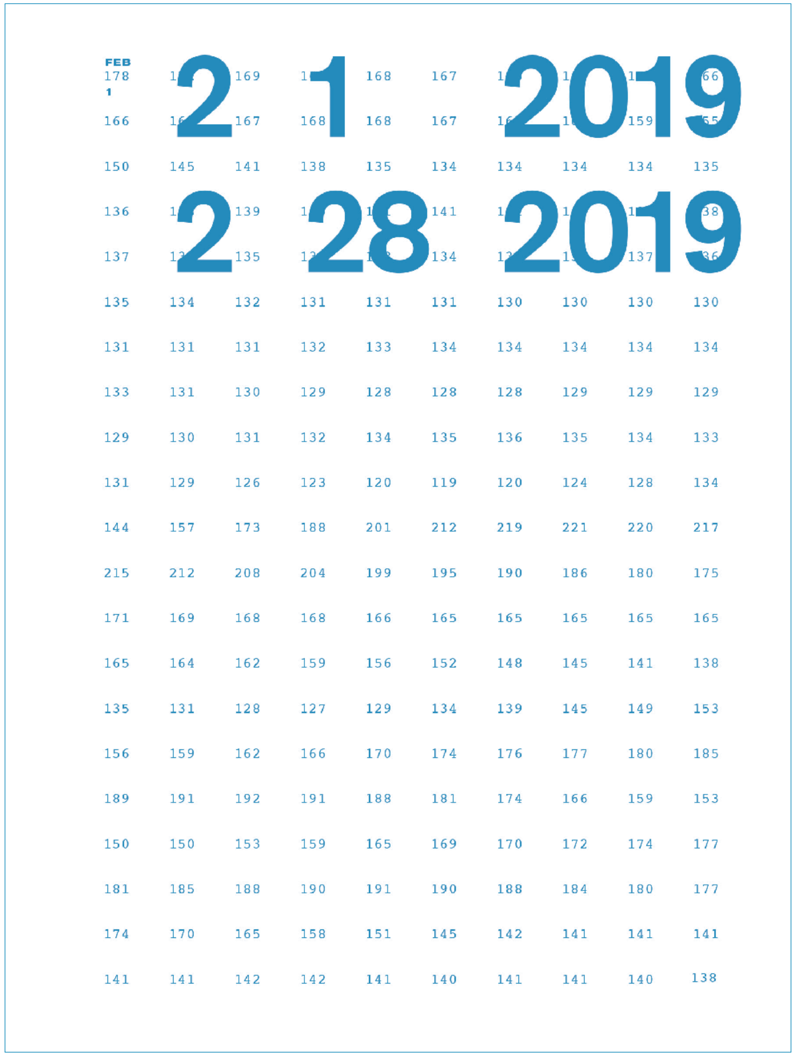
High-risk pools are state programs that offer health insurance to residents who, because of pre-existing medical conditions, are unable to purchase affordable coverage in the individual market. High-risk pools share a common structure and some similarities but differ by state in many ways including: eligibility, benefit design and pre-existing condition exclusions, premium costs, cost-sharing, subsidy programs, administration, and funding sources.<?>

Hyperglycemia

High level of glucose in the bloodstream. For people with diabetes this is typically seen as 180 mg/dl or higher. For the nondiabetic as 140 mg/dl or higher when fasting. Any diabetic-level exposure to glucose in the bloodstream can result in damage to the vascular system. Symptoms of serious hyperglycemia (250 mg/dl or higher) might include nausea, fatigue, bad breath, thirst, frequent urination. Prolonged or extreme hyperglycemia can also result in diabetic ketoacidosis (DKA) which requires hospitalization and can be fatal.

Hypoglycemia

Low level of glucose in the bloodstream. For people with diabetes this is typically seen as 70 mg/dl or lower. For the nondiabetic as 80 mg/dl or lower when fasting. Symptoms of serious hypoglycemia (54 mg/dl or lower) might include hunger, dizziness, fatigue, reduction of cognitive function. Prolonged or extreme hypoglycemia can also result in damage to



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150	145	141	138	135	134	134	134	134	135
136	[illegible]	139	[illegible]	[illegible]	141	[illegible]	[illegible]	[illegible]	[illegible]
137	[illegible]	135	[illegible]	[illegible]	134	[illegible]	[illegible]	137	[illegible]
135	134	132	131	131	131	130	130	130	130
131	131	131	132	133	134	134	134	134	134
133	131	130	129	128	128	128	129	129	129
129	130	131	132	134	135	136	135	134	133
131	129	126	123	120	119	120	124	128	134
144	157	173	188	201	212	219	221	220	217
215	212	208	204	199	195	190	186	180	175
171	169	168	168	166	165	165	165	165	165
165	164	162	159	156	152	148	145	141	138
135	131	128	127	129	134	139	145	149	153
156	159	162	166	170	174	176	177	180	185
189	191	192	191	188	181	174	166	159	153
150	150	153	159	165	169	170	172	174	177
181	185	188	190	191	190	188	184	180	177
174	170	165	158	151	145	142	141	141	141
141	141	142	142	141	140	141	141	140	138

6. Logbook

The logbook is a typographic record of the condition. If one were placed in the hands of a person with diabetes, they could read it like a novel. On the other hand, even a person without diabetes can in some way understand the numerous pages of running numbers that speak to the relentlessness of the condition. The logbook is a central component of record-keeping for people with diabetes. Documentation and analysis is ongoing. Values are always moving.

FEB 178 1	172	169	169	168	167	166	165	165	166
166	166	167	168	168	167	166	163	159	155
150	145	141	138	135	134	134	134	134	135
136	138	139	140	141	141	141	140	139	138
137	136	135	134	133	134	135	137	137	136
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129	130	131	132	134	135	136	135	134	133
131	129	126	123	120	119	120	124	128	134
144	157	173	188	201	212	219	221	220	217
215	212	208	204	199	195	190	186	180	175
171	169	168	168	166	165	165	165	165	165
165	164	162	159	156	152	148	145	141	138
135	131	128	127	129	134	139	145	149	153
156	159	162	166	170	174	176	177	180	185
189	191	192	191	188	181	174	166	159	153
150	150	153	159	165	169	170	172	174	177
181	185	188	190	191	190	188	184	180	177
174	170	165	158	151	145	142	141	141	141
141	141	142	142	141	140	141	141	140	138

136	133	130	127	125	124	123	122	121	120
119	119	120	122	124	126	127	127	126	125
124	122	119	114	111	109	109	109	110	111
113	117	125	135	147	161	172	177	178	177
180	183	187	192	196	195	193	191	196	205
216	227	235	241	244	245	244	243	243	243
243	243	242	241	240	239	239	239	240	241
242	243	245	246	246	247	248	251 2	254	256
256	255	253	254	256	259	261	264	265	266
265	266	266	268	270	272	273	272	271	270
269	267	264	261	259	259	257	253	247	240
235	230	227	225	223	221	217	214	212	211
210	209	208	206	204	202	200	199	199	198
197	196	194	191	188	186	185	184	183	183
183	184	184	183	182	179	177	175	174	173
173	173	172	171	171	170	169	169	168	167
166	165	164	163	161	161	161	161	161	161
162	163	162	161	160	160	161	161	161	160
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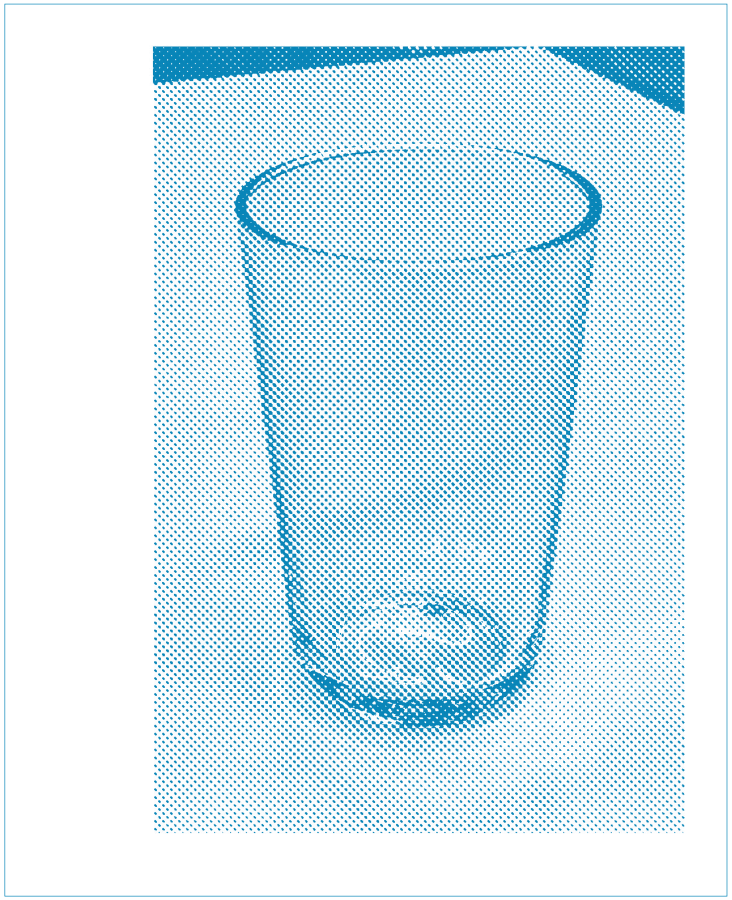


7. Memory

A simple water glass represents my earliest memory as a person with diabetes. I can remember some nights before being diagnosed, climbing up on to the countertop in the kitchen to take a glass from the cupboard and drink. It is a memory shared by many people with diabetes, and a simple reminder of a particular relationship to an everyday object. I had long disregarded a lot of my diabetes-related memories. Writing this text was a good way to remember. Sharing stories made me realize how much I and others with this experience have in common.

I have been type 1 for 28 years. Since I was 6 years old. I have few substantial memories before that time. I remember the day of the diagnosis. I remember the doctor. I remember my mom. Once the doctor had left the examination room asking her: “am I going to die?” I think she said: “no.” I remember the nurse pricking my finger, testing the blood glucose level more than once. Maybe something wasn’t right. Maybe three different times. I remember the office, the lab in the hallway. I liked the wooden toys in the waiting room. I can remember some nights before, in the dark, climbing up onto the kitchen counter to pull a water glass and drink. I remember being home later that afternoon, packing suitcases to take to the hospital. A rolling TV cart with a few video games. The hospital staff

were friendly. I remember my grandmother being there. My new doctor. I remember my dog. I remember being 7 or 8 in early diabetes education groups, nutrition groups, sterile rooms. And a diabetes summer camp, less so. I remember at 9 swabbing alcohol, drawing the syringe, pinching up the skin against the frame of the door and injecting myself in the arm for the first time. Proud. Birthday parties asking if there was sugar in the pizza sauce, refusing cake, or having cake refused to me by others. “I can cut the frosting off!” Calling each pizzeria to ask if there was sugar in the sauce. Some not sure. I could eat snacks in the classroom. I remember my friends telling me what happened when I passed out in the school lunchroom. Low blood-glucose. I remember feeling tired. The taste of

1
Novo Nordisk Fiasp®
(insulin aspart injections) 100 units/ml
(U-100)

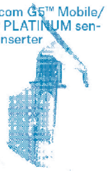
2
BD Insulin Syringe
with BD Ultra-Fine™
needle, 8mm length,
U-100

3
Medtronic 722
Paradigm® MiniMed
insulin pump

4
Medtronic MiniMed
Reservoir 3ml

5
Medtronic MiniMed
Quick-set® Paradigm®
infusion set

6
Dexcom G5™ Mobile/
G4® PLATINUM
sensor



7
Dexcom G5™ Mobile/
G4® PLATINUM sensor inserter

8
Dexcom G5™ Mobile/
G4® PLATINUM
transmitter

9
OneTouch® Ultra-Mini® blood glucose
monitor

10
OneTouch Ultra®
blood glucose test
strips (50 ct.)

11
OneTouch Delica®
lancet

12
OneTouch Delica®
lancing device

13
Bayer Ketostix®
reagent strips for
urinalysis

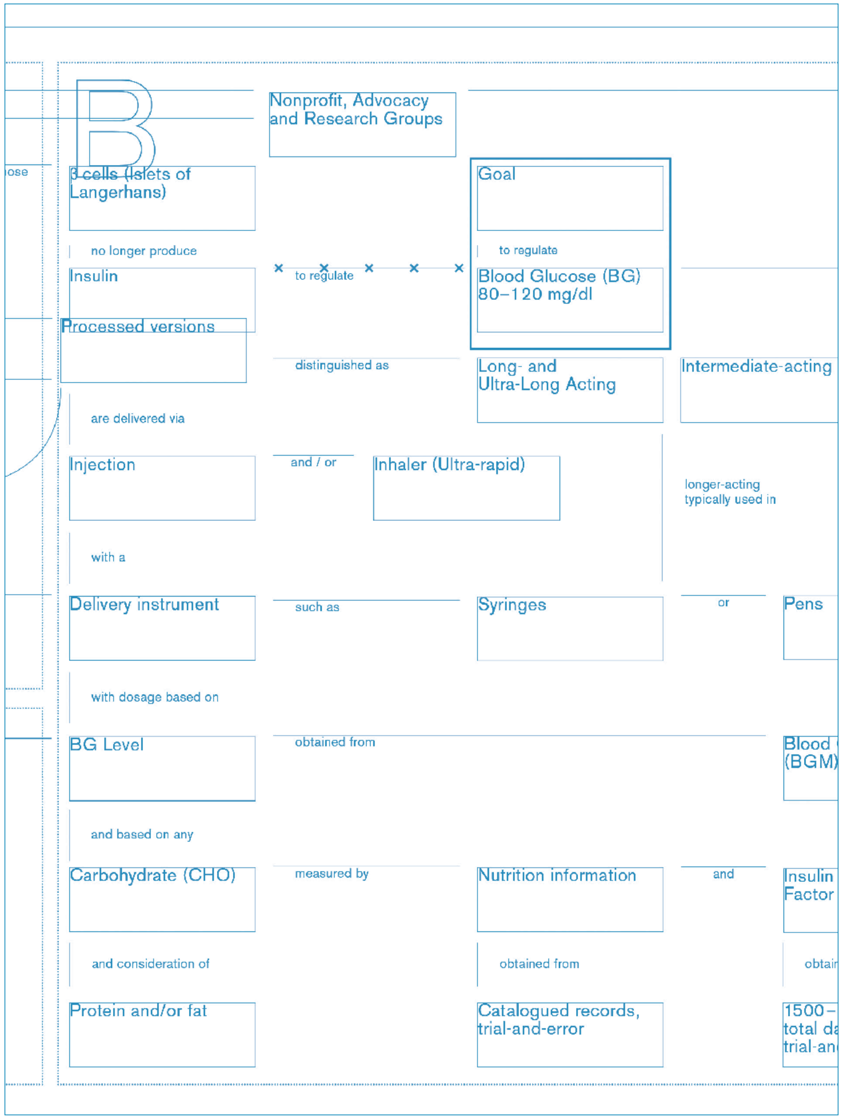
14
Energizer® lithium
battery AAA E92

15
Eli Lily Glucagon
Emergency Kit, 1mg
Glucagon vial, 1ml diluting solution syringe

16
OpenAPS (Intel®
Edison),Tic Tac
box

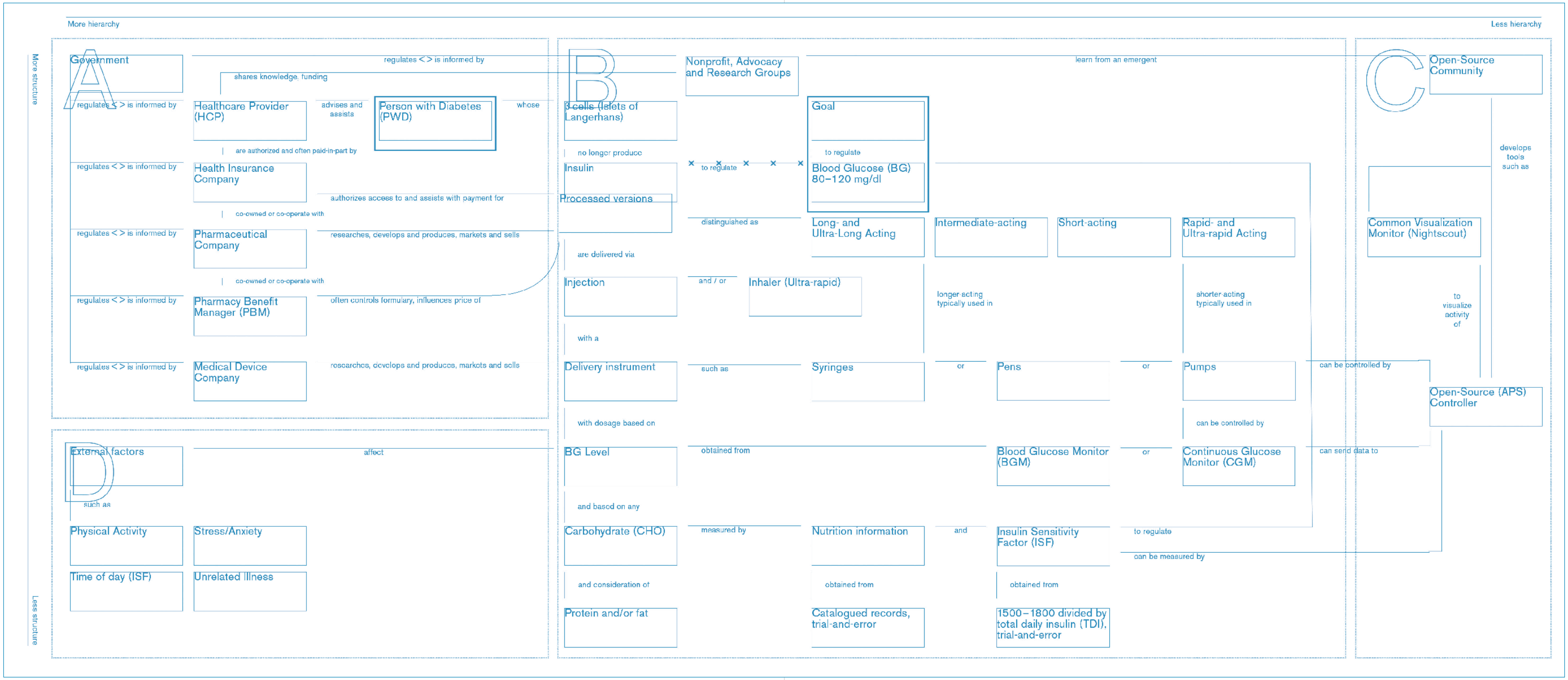
8. Materials

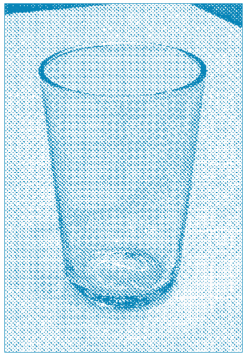
Tools for monitoring, sensing, testing, and delivering, are always present but rarely visible to others. The manufacturers, product names, and forms may change, and new technologies may be introduced, and so it is a modular kit of many components from many places, which takes on new forms over time.

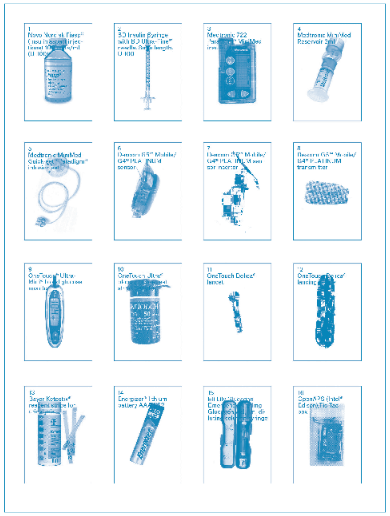


9. System

In thinking back to the onset (1), what form does the man-made system that we have created to correct diabetes take in contrast to the organic system? By looking at what components operate at what levels to coordinate the task of regulating blood-glucose, we can see that the system is complex. A conversation with visiting designer Hugh Dubberly led to the idea of mapping this out. The diagram becomes a point of discussion, a place to examine where and by what means this system may work, manage, or fail.


More hierarchy
Less hierarchy
More structure
Less structure
A
Government
regulates < > is informed by
shares knowledge, funding
regulates < > is informed by
Healthcare Provider (HCP)
advises and assists
Person with Diabetes (PWD)
whose
are authorized and often paid-in-part by
regulates < > is informed by
Health Insurance Company
authorizes access to and assists with payment for
co-owned or co-operate with
regulates < > is informed by
Pharmaceutical Company
researches, develops and produces, markets and sells
co-owned or co-operate with
regulates < > is informed by
Pharmacy Benefit Manager (PBM)
often controls formulary, influences price of
regulates < > is informed by
Medical Device Company
researches, develops and produces, markets and sells
B
Nonprofit, Advocacy and Research Groups
learn from an emergent
β cells (Islets of Langerhans)
no longer produce
Insulin
Processed versions
× to regulate × × × ×
Goal
to regulate
Blood Glucose (BG) 80–120 mg/dl
distinguished as
Long- and Ultra-Long Acting
Intermediate-acting
Short-acting
Rapid- and Ultra-rapid Acting
are delivered via
Injection
and / or
Inhaler (Ultra-rapid)
longer-acting typically used in
shorter-acting typically used in
with a
Delivery instrument
such as
Syringes
or
Pens
or
Pumps
can be controlled by
with dosage based on
BG Level
obtained from
Blood Glucose Monitor (BGM)
or
Continuous Glucose Monitor (CGM)
can send data to
and based on any
Carbohydrate (CHO)
measured by
Nutrition information
and
Insulin Sensitivity Factor (ISF)
to regulate
can be measured by
and consideration of
Protein and/or fat
obtained from
Catalogued records, trial-and-error
obtained from
1500–1800 divided by total daily insulin (TDI), trial-and-error
C
Open-Source Community
develops tools such as
Common Visualization Monitor (Nightscout)
to visualize activity of
Open-Source (APS) Controller
can be controlled by
D
External factors
affect
such as
Physical Activity
Stress/Anxiety
Time of day (ISF)
Unrelated Illness





in the blood and is the main sugar that the body manufactures. The body makes glucose from all three elements of food—protein, fats, and carbohydrates—the largest amount of glucose derives from carbohydrates. Glucose serves as the major source of energy for living cells. However, cells cannot use glucose without the help of insulin.

Glucose Gel
A gel made of glucose which typically has 15g of carbohydrate and 15g of glucose in a single serving. The gel is designed specifically to treat hypoglycemia for regular measure and fast absorption. In particular, they can be administered by another person in the event of hypoglycemic unconsciousness. They are made by a number of brands and come in a variety of flavors.

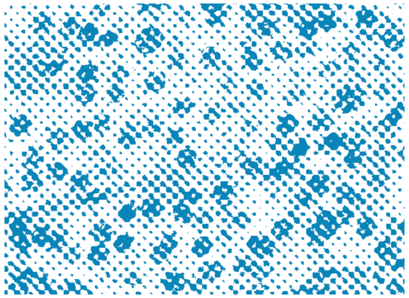
Glucose Tablet
A large, chewable, candy-like pill made of glucose which typically has 5g of carbohydrate and 5g of glucose. The tablet is designed

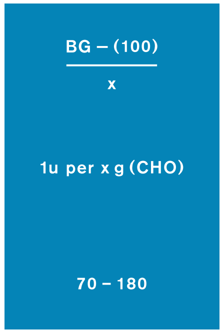
of sickness, while in the long-term can contribute to oxidative stress and complications. The measurement is important, as while an A1C number at or below 7% may indicate good control, it is only an average. GV shows the quality of control over time.

GlycoMark (AG 1,5)
An indicator of glycosuria. When blood glucose is well-controlled, glucose and 1,5-AG circulate in the bloodstream. The molecules are filtered by the kidneys and reabsorbed by the body. Urinary 1,5-AG is equal to the ingested 1,5-AG. When glucose exceeds the renal threshold (>180 mg/dL), glycosuria blocks reabsorption of 1,5-AG. 1,5-AG is excreted in the urine resulting in lower 1,5-AG levels. The GlycoMark test measures 1,5-AG from a serum or EDTA plasma blood sample.

h

Hemoglobin A1c
A blood test which results in



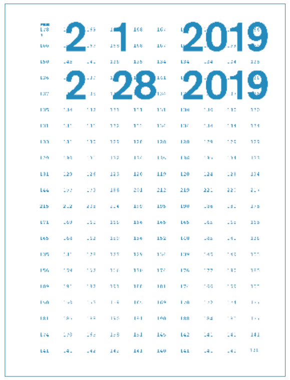


BG – (100)

x

1u per x g (CHO)

70 – 180



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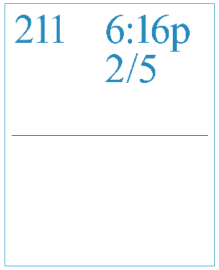
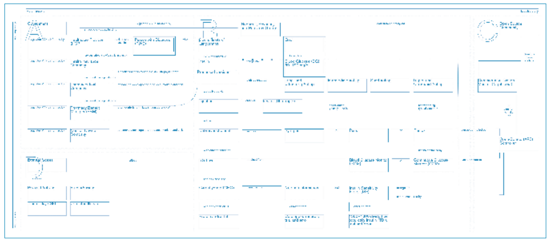
2 28 2019



211 6:16p
2/5



10. Catalogue

Altogether these descriptions create a catalogue. While no one could expect to take away a complete understanding of type 1 diabetes, or even of the particular facets from any one gesture, the set begins an expression of the layers of experience of a person living with type 1 diabetes at this moment. In the beginning, the hope was that what perspective about the condition emerged from these pieces could begin to illustrate a new map, a way to try and move forward from an old way of seeing.

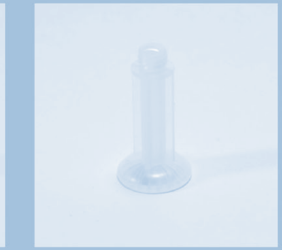
1

2

3

4

5



6

7

8

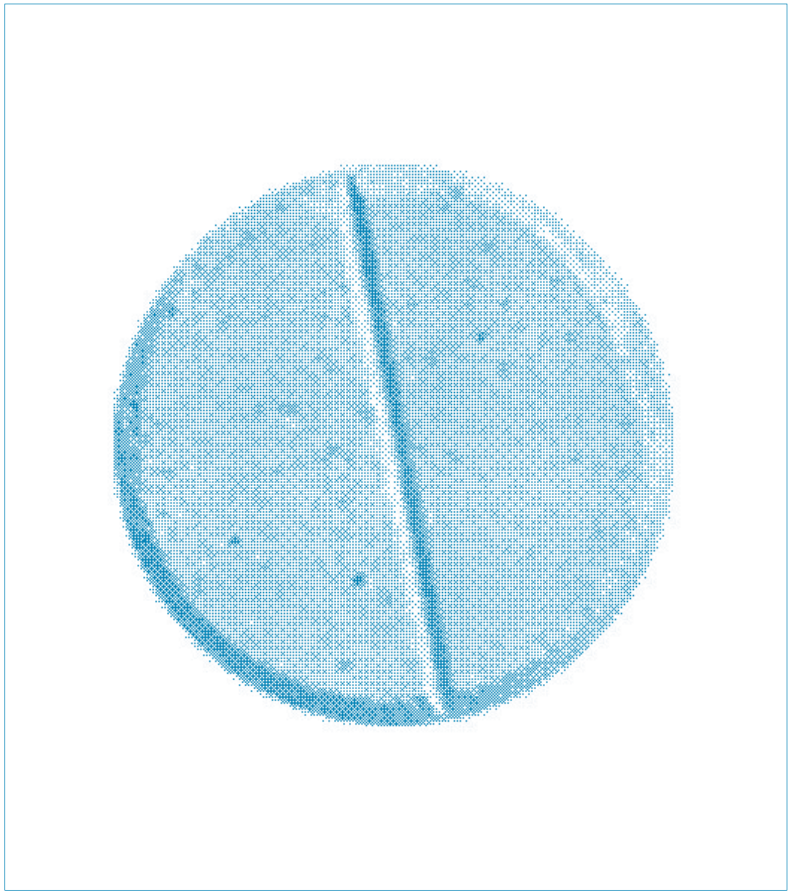
9

11. Waste

The component pieces from a single infusion-set change show both the need to consider alternative materials in light of the increase in single-use plastic waste as therapies have evolved. At the same time, the basic forms of these parts that are used and tossed away every few days can be recognized for a moment.

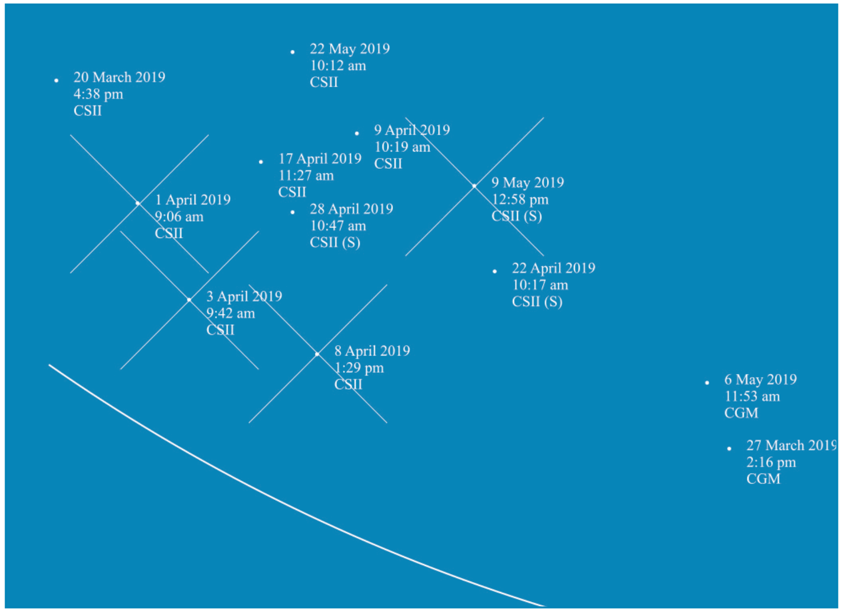
12. Detail

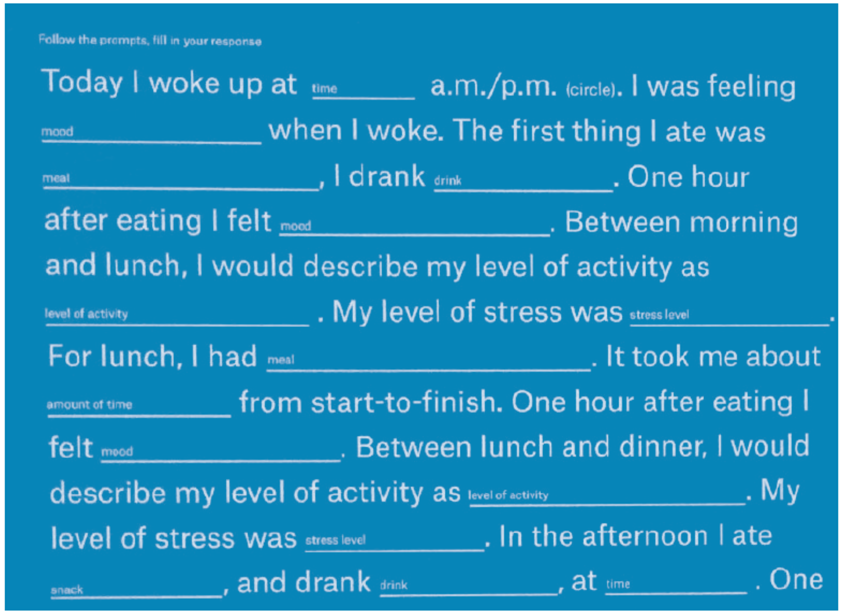
Looking closely, there are small parts of the everyday materials that escape view or are never noticed. The wrap-around label on a bottle of insulin, the fold-out notes from inside the box. Even the small, finely-printed letters from the back of an insulin pump take on a new life when enlarged. Like the logbook (6) which is also generated almost automatically from the material, these elements begin to have a voice on their own.



13. Correction

In balance with insulin is glucose. At a certain point in the process I returned to the recommended tool of glucose tablets from what I had been using, Haribo gummy bears. A specific moment, and a return to earliest instruction.





Follow the prompts, fill in your response

Today I woke up at time ______ a.m./p.m. (circle). I was feeling mood ______ when I woke. The first thing I ate was meal ______, I drank drink ______. One hour after eating I felt mood ______. Between morning and lunch, I would describe my level of activity as level of activity ______. My level of stress was stress level ______. For lunch, I had meal ______. It took me about amount of time ______ from start-to-finish. One hour after eating I felt mood ______. Between lunch and dinner, I would describe my level of activity as level of activity ______. My level of stress was stress level ______. In the afternoon I ate snack ______, and drank drink ______, at time ______. One

15. Inversion

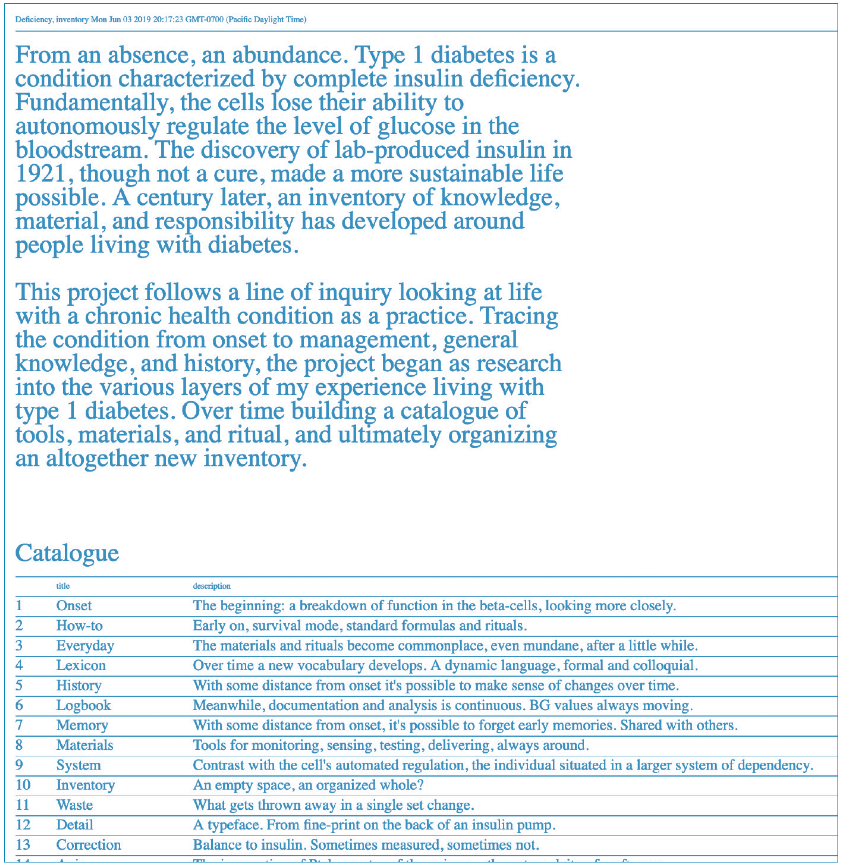
If the early process was focused on the materials required by a person with type 1 diabetes, the work produced in the later stage is more generative, a way of growing through production. If, looking back, I felt that I would need to depend on these materials and methods, moving forward would depend on my ability to try and go beyond them.

The process of making this work became a kind of therapy, to work through ways of reckoning with my interests as someone examining both their own methods of design and life with diabetes. Picking up on scraps or moments in the project, recycling, reframing pieces from my own process, trying things out, working through things. A typeface, documentation of fingersticks, a 24-hr glucose level data rendered in sound, a constellation map of injection sites.

changing the Dexcom G6 sensor,
continuous glucose monitor

16. How-to

Remembering the early example of a few equations and a prescription. Education for people with diabetes can always improve. The development of the online community is a recent change. It’s not surprising to see a video on YouTube with a person describing how to take insulin, or describe facets of their experience first-hand. This wasn’t always the case. Like many of these components, over time there has been significant change in how we understand and learn to manage the condition, and from whom we learn.



Deficiency, inventory Mon Jun 03 2019 20:17:23 GMT-0700 (Pacific Daylight Time)

From an absence, an abundance. Type 1 diabetes is a condition characterized by complete insulin deficiency. Fundamentally, the cells lose their ability to autonomously regulate the level of glucose in the bloodstream. The discovery of lab-produced insulin in 1921, though not a cure, made a more sustainable life possible. A century later, an inventory of knowledge, material, and responsibility has developed around people living with diabetes.

This project follows a line of inquiry looking at life with a chronic health condition as a practice. Tracing the condition from onset to management, general knowledge, and history, the project began as research into the various layers of my experience living with type 1 diabetes. Over time building a catalogue of tools, materials, and ritual, and ultimately organizing an altogether new inventory.

Catalogue

	title	description
1	Onset	The beginning: a breakdown of function in the beta-cells, looking more closely.
2	How-to	Early on, survival mode, standard formulas and rituals.
3	Everyday	The materials and rituals become commonplace, even mundane, after a little while.
4	Lexicon	Over time a new vocabulary develops. A dynamic language, formal and colloquial.
5	History	With some distance from onset it's possible to make sense of changes over time.
6	Logbook	Meanwhile, documentation and analysis is continuous. BG values always moving.
7	Memory	With some distance from onset, it's possible to forget early memories. Shared with others.
8	Materials	Tools for monitoring, sensing, testing, delivering, always around.
9	System	Contrast with the cell's automated regulation, the individual situated in a larger system of dependency.
10	Inventory	An empty space, an organized whole?
11	Waste	What gets thrown away in a single set change.
12	Detail	A typeface. From fine-print on the back of an insulin pump.
13	Correction	Balance to insulin. Sometimes measured, sometimes not.

Compression

The process is placed into a website, and the content can take on a new form. A new meeting point for dialogue, and a place from which to share with others.

Conclusion

The early research and study was liberating: I felt excited to work in a field that I had always been connected to but distanced myself from because I was afraid to engage with it. To meet others with type 1 diabetes and learn from them, to share stories, was a new feeling. Working on OpenAPS and expanding on that feeling in Arnhem, I felt connected to the material—and to being a person with diabetes—in a new way. It was empowering to understand a personal place from which to work.

Through the early process lacking the confidence to place my experience with diabetes in a familar setting, by the end, was is clear to me what is obvious to all of the artists and designers I had been thinking of as I began to try and make formal abstraction of the map, wondering how they might approach the same issue: beyond form alone it is the relationship of those and their lived experience, sensitivity, and values which inform the work they create. Like learning to care for my practice as a person with type 1 diabetes, I am encouraged to continue to revisit the work with new perspective to find and build new forms, language, and process.

It is a feedback loop: returning to step one and working from the beginning as a new phase, again and again, organizing and expanding the components again, and beginning to develop a personal method.

Outcomes

During the best moments of the project there was a particularly good feeling. When the methodology is aligned with personal experience, the work is better. Looking back at the process as a whole, some outcomes include:

New knowledge: Produced through an unlikely engagement with familiar material. Engaging idle knowledge in new forms leads to better understanding, reflection, and growth—the work becomes a meeting point for developing a practice. This first became clear to me in Arnhem, but over time becomes clearer still.

New methodology: Finding ways to recognize moments in one's work that are informed directly by personal experience and search.

New community: Knowledge becomes more dynamic in shared interest with others. Helping someone with their experience through sharing my own, and at the same time continuing to learn from others. Being a part of the type 1 diabetes community as an active participant has changed my practice.

Improved health: By being conscious of type 1 diabetes, and looking for new ways to engage with it, there was an unexpected but significant improvement in control of the condition over the course of the project.

Afterword

There remain serious issues in this country and around the world for people living with type 1 diabetes. In 2019, people in the United States still die because they do not have access to affordable insulin. No matter how advanced the technology, or how sophisticated the knowledge available to those living with type 1 diabetes, it is difficult to celebrate our successes when the shortcomings are so significant. No one in this or any country should die because of lack of access to insulin. Meeting people working on this front has led to some of the most motivating conversations during the project.

Acknowledgments

To Elina
To my parents
To my brother
To my friends

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Axel Roesler, committee

Rebecca Cummins
Stephen Groening
Aaron Flint Jamison
Jeffrey T. Knight
Ann Langford-Fuchs
Kolya Rice
Marek Wieczorek
Emily Zimmerman

Dr. Irl Hirsch
Thacher Hussain
Scott Leibrand
Dana Lewis

Thomas Castro
The GDA group

The classes of 2018 and 2020
My cohort, our group

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