

SUPPLEMENTAL MATERIALS: Identifying the unmet health needs of patients with congenital hypogonadotropic hypogonadism using a web-based needs assessment: Implications for online interventions and peer-to-peer support

1. Summary of online survey results

2. Supplemental Figure S1: Patient-reported longest duration without healthcare among CHH men.

1. Summary of online survey results

1A. Sociodemographic information

Age: [open ended response]

19-29 yrs: 32/105 (30%)
30-39 yrs: 39/105 (37%)
40-49 yrs: 19/105 (18%)
50-59 yrs: 11/105 (10%)
60+ yrs: 4/105 (4%)

Relationship status: [multiple choice]

never been in a relationship: 24/104 (23%)
single: 25/104 (24%)
in a relationship: 16/104 (15%)
married: 38/104 (36%)
divorced: 1/104 (1%)

Religion: [open-ended question question]

Christian (protestant & evangelical): 25/90 (28%)
Roman Catholicism: 17/90 (19%)
Orthodox Christianity: 3/90 (3%)
(Eastern & Russian)
Islam: 5/90 (6%)
Judaism: 2/90 (2%)
Buddhism: 1/90 (1%)
Hinduism: 1/90 (1%)
Other: 10/90 (11%)
(Paganism, Mormonism, Jehovah's Witness, secular humanist, personal faith)
Atheism: 10/90 (11%)
None: 16/90 (18%)

Highest level of education: [multiple choice]

elementary: 0/105 (0%)
high school/vocational: 36/105 (34%)
university: 38/105 (36%)
post-graduate: 31/105 (30%)

Employment: [multiple choice]

student: 9/104 (9%)

working part-time: 9/104 (9%)

working full-time: 70/104 (67%)

retired: 6/104 (6%)

unemployed: 10/104 (10%)

Type of employment: [open ended question - responses included]

<u><i>Business & Finance</i></u> Business analyst/consultant Economist Finance	<u><i>Teaching & Education</i></u> Teacher Professor School administrator
<u><i>Law & Legal Services</i></u> Attorney Legal assistant Legislative consultant	<u><i>Psychology & social Work</i></u> School Counselor Counselor/mediator
<u><i>Healthcare & Science</i></u> Dentist Physician Nurse Pharmacist Ambulance staff Patient care assistant Translation services Biomedical scientist Chemist/Lab Technician Hospital finance/administration	<u><i>Engineering & Information Technology (IT)</i></u> Engineer Electrical Engineer Applications engineer Network Engineer Computer systems management Software developer Computer programming IT technician
<u><i>Service & retail</i></u> Clerk Sales/Retail Personal trainer Call center/customer services	<u><i>Management & supervisors</i></u> Manager - small business Manager – manufacturing warehouse supervisor Purchasing manager
<u><i>Laborer & Manufacturing</i></u> Construction Lawn care Airline baggage Warehouse Milling machine operator Quality control technician	<u><i>Transportation</i></u> Public transportation driver Limousine Service Truck driver
<u><i>Civil Service</i></u> civil servant Postal worker Juvenile services	<u><i>Arts & Entertainment</i></u> Composer Performing arts Graphic design
<u><i>Religious clergy</i></u> clergy Buddhist monk	

1B. Healthcare literacy

- *How confident are you filling out medical forms by yourself?*
Extremely: 45/105 (43%)
quite a bit: 34/105 (32%)
somewhat: 25/105 (24%)
a little bit: 1/105 (1%)
not at all: 0/105 (0%)

1C. Health information seeking patterns:

- *Where have you searched for information to learn about CHH? (check all that apply)*
internet (i.e. Wikipedia): 101/105 (96%)
online community (social media/chat): 81/105 (77%)
healthcare professionals: 74/105 (70%)
medical literature: 49/105 (47%)
family/friends: 12/105 (11%)
other: 0/105 (0%)
- *From your experience, please rank the 3 most important sources:*
healthcare professionals: weighted score 166
internet (i.e. wikipedia): weighted score 150
online community (social media/chat): weighted score 146
medical literature: weighted score 93
family/friends: weighted score 18

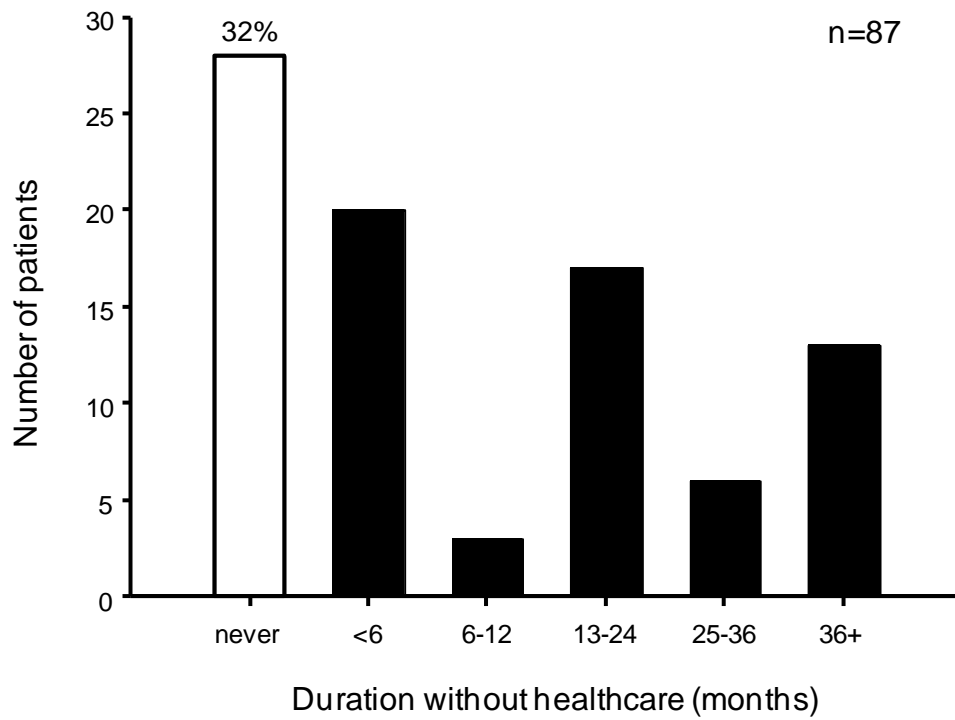
1D. Interactions with healthcare system/providers

- *Within the healthcare system, have you ever experienced discrimination because of CHH?*
No: 89/105 (85%)
Yes: 16/105 (15%)
- *Have you ever had a consultation or received treatment at an academic health center (such as a teaching hospital or research center)?*
No: 51/105 (49%)
Yes: 54/105 (51%)
- *Is there a healthcare provider (i.e. doctor or nurse) who you feel really understands the medical aspects of your CHH?*
No: 35/105 (33%)
Yes: 70/105 (67%)
- *Is there a healthcare provider (i.e. doctor or nurse) who you feel understands your feelings about having CHH?*
No: 65/104 (62.5%)
Yes: 39/104 (37.5%)
- *Has a healthcare provider (either general practitioner or specialist) ever offered you counseling or a referral for professional counseling?*
No: 79/105 (75%)
Yes: 26/105 (25%)

1E. *Diagnosis, treatment & adherence*

- *At what age were you diagnosed with CHH?* [open ended question]
mean±SD: 18±6 years
range: neonatal – 32 years
median: 18 years
- *Lifetime duration of treatment* [calculated from start of treatment]
mean±SD: 18±12 years
range: 0 – 46 years
median: 16 years
- *What treatments have you had for CHH? (check all that apply)*
testosterone (injections, pellets, patches, or gel): 99/105
gonadotropin/fertility injections: 37/105
none: 3/105 (two recently diagnosed patients)
- *What is the longest period of time that you have gone without medical care (not under the care of a doctor or healthcare provider for your CHH):* [open-ended]
Never: 24/93 (26%)
<6 months: 27/93 (29%)
6-12 months: 7/93 (8%)
13-24 months: 15/93 (16%)
25-36 months: 8/93 (9%)
36+ months: 12/93 (12%)
- *What is the longest period of time that you have been off your CHH medication (not at the instruction of your doctor or healthcare provider):* [open-ended]
never: 28/87 (32%)
<6 months: 20/87 (23%)
6-12 months: 3/87 (3%)
13-24 months: 17/87 (20%)
25-36 months: 6/87 (7%)
36+ months: 13/87 (15%)

Figure S1. Patient-reported longest duration without healthcare among CHH men.



Healthcare continuity as assessed by patient-reported longest period without contact with a healthcare professional (n=87). In total, 32% of CHH men reported never having a break in their continuity of healthcare while 41% had gaps in care exceeding 1 year.