

IPOPI COVID-19 Learning Expedition



July - September 2020



www.ipopi.org

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1.0 Introduction

The IPOPI COVID-19 Learning Expedition (LEX) was launched to identify, analyse and provide recommendations on issues brought about by the COVID-19 pandemic for patients with primary immunodeficiency (PID). As people with PID are susceptible to infections, the COVID-19 pandemic has caused uncertainty and a desire to learn how to best cope with this condition in the current circumstances. Many issues existed prior to the pandemic, but the pandemic has spotlighted these for people with chronic and rare diseases such as members of the PID community. Thus, the aim of the LEX project was to assist our global PID community when coping with this health crisis and to strengthen patient expertise on topics where they need to have their voices heard.

The structure of the COVID-19 LEX project was global, as the COVID-19 pandemic affects all countries worldwide. This was both reflected in the origin of the participants and in the discussions held, highlighting perspectives from various regions. This report can thus be considered a global content base, produced with the intention of supporting IPOPI's National Member Organisations (NMOs) in their work during the COVID-19 pandemic, or in future similar scenarios. We do not believe in a "one size fits all approach" for COVID-19, instead we gather the common experiences and recommendations in this content base, for IPOPI members to tailor to their own needs. We are proud of how the report allows for the patient perspective to be centred and encourages patient expertise to be used and shared by IPOPI members from all over the world.

2.0 Methodology

2.1 A LEX team

IPOPI's National Member Organisations were invited to take part in the Learning Expedition project. The members of the LEX group are patient leaders (board members of national patient organisations, or regional delegates), meaning people deeply committed to their organisations, who were interested in the process and willing to engage in it.



Acknowledgments to our great LEX team for their time, input and cooperation!

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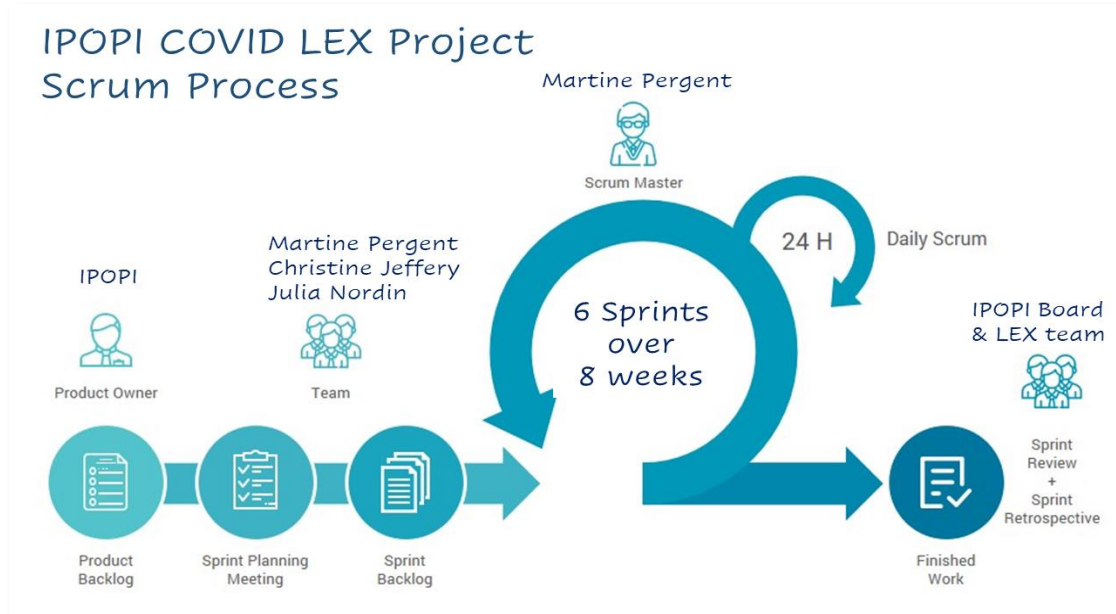
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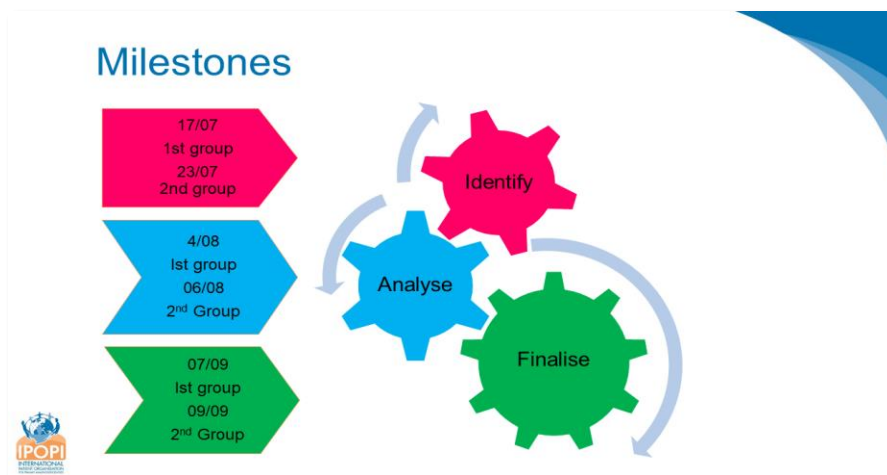
2.2 Agile scrum process

The IPOPI LEX project used an agile scrum process described in the overview below.



The attendees were split in 2 groups to manage the different time zones, with six sprint international meeting dates:

- | | |
|---------------|---------------|
| 1. 17/07/2020 | 4. 06/08/2020 |
| 2. 23/07/2020 | 5. 07/09/2020 |
| 3. 04/08/2020 | 6. 09/09/2020 |



three issues affect PID patients in particular. Based on this it is clear that PID patients face a double burden. Not only are they affected more than the average citizen by issues concerning the general public, but also weighed down by additional core issues specifically targeting PID patients. The additional vulnerability this creates is something vitally important to address when discussing the effects of this pandemic for PID patients.

4.1 General public perception and behaviour

A clear example of the double weight on the shoulders of PID patients is reflected in the core issue concerning general public perception and behaviour. If the general public chooses not to keep their social distance or follow personal protection and hygiene it poses a problem for people in general as the number of infections may rise. The potential rise in the infection rate is a problem concerning the whole population in a country, but it is an even greater problem for PID patients. PID patients are susceptible to infections and their experience of an infection and its outcomes is much worse than that of the general population. Therefore, the fear of contracting COVID-19 is multiplied. A worldwide spread of a new infectious disease greatly increases their distress, something further provoked by a general public who may not follow regulations. Unfortunately, the general public does not possess enough knowledge about these rare conditions to understand the impact they can have on their health and wellbeing. Despite LEX participants testified that the general knowledge about the immune system has increased during the pandemic, this issue remains for PID patients.

Some examples fit into multiple core issues and may be repeated in more than one table.

General public perception and behaviour examples

CORE ISSUE	EXAMPLES
General public perception and behaviour	Positive examples <ul style="list-style-type: none"> + People are learning what is important in life, getting back to basics + General public increasingly wearing masks + General public not afraid to condemn those who say that COVID-19 is a myth, or that rules of wearing masks are against their human rights + Raised awareness of the implications of COVID-19 and the need to isolate if you are diagnosed or show symptoms + Communication is easier (less need for face-to-face communication) + Social media increasingly important + Social media promoting “idiots” and the public condemning them + Raised awareness of the implications of COVID-19 and the need to get tested + Raised awareness of the implications of COVID-19 and the need to isolate if you are diagnosed or show symptoms + Raised awareness of pandemics and their impact on the world

	Negative examples <ul style="list-style-type: none"> - General public not keeping distance - General public becoming complacent - Children don't understand social distancing - People not following the isolation rules after being tested for COVID-19 - People lying about COVID-19 and travel (selfish behaviour) - Parts of the general population not wearing masks - Some public perceptions perceiving that COVID-19 restrictions infringe on human rights - Culturally, physical distance between people differs very much from country to country - Unclear messages, different local, regional and national rules - Globally, Governments and Public Health Authorities not united in their implementation of actions to slow transmission of COVID-19 - No relative information or data (COVID-19 versus other coronaviruses or other lethal viruses or medical conditions) - Lack of information about vaccines in general (developing and manufacturing capability) - Misunderstandings of the severity of COVID-19
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4.2 Lifestyle impact

Another example of the struggle for PID patients is the lifestyle impact that has come as a result of COVID-19. Many people have drastically seen their lives change during the past six months, with new staying-at-home routines and a more isolated lifestyle established. Even though staying away from crowds and following hygiene precautions may be a common practice amongst PID patients, this new lifestyle is a challenge for the community. In addition to this, one of the main points raised by the participants during the learning expedition was that lack of concrete information poses a real test for them. This is yet another issue that concerns the general public but affects PID patients on a deeper level as their fear of infection generally is stronger. Not only is there very little fact-based concrete information available on how this virus behaves and how people can protect themselves from it, but the steady influx of misinformation adds to this confusion. This area is in great need of improvement for PID patients.

Lifestyle impact examples

CORE ISSUE	EXAMPLES
Lifestyle impact	Positive examples <ul style="list-style-type: none"> + More webinars mean patients can't pick up infections from others + Online group meetings and conferences + Working from home + Increased relaxation time to develop new hobbies or taking up old ones + More flexibility, adaptability + Easier to communicate with family due to online meeting platforms + Telework (working from home, saving time and money) + Telehealth (access to medicine and care without leaving your house)

	<ul style="list-style-type: none"> + Shopping via internet and goods being delivered to home + Shopping, just getting what you need, nothing more + Increased access to hand sanitisers and masks + Businesses seeking new ways of trading
	<p>Negative examples</p> <ul style="list-style-type: none"> - Lack of concrete information on how to lead a daily life (how to deal with products and clothes after shopping, how long to keep a homemade mask, how to care for a family when a member is a patient etc) - Uncertainty for children's schooling, lack of knowledge of safeguarding measures - Basic school education has become more difficult (people struggling with moving online) - Long term isolation, not so hard at beginning but increasingly difficult with time - Not being able to socialise with family or friends - As COVID-19 progresses, shopping is increasingly difficult - Difficult to buy food and shop, not everyone can have home delivery or internet access - Access to hand sanitisers and masks difficult due to panic purchases - Change of habits (transport, shopping, moving), differences in ability to adapt - Financial impact - Job insecurity - Job loss, difficult to buy food and other essential items and access healthcare - Income erosion, financial struggle - Travelling is difficult, special preparation needed

4.3 Emotional/social and mental health

The emotional, psychological and social issues were also raised as an issue by participants, mentioning that the many unknowns and the new lifestyle has led to an increase in mental health issues and feelings of loneliness for PID patients. The uncertain future and the lack of information about how great the risk is for severe COVID-19 infection in patients with PIDs adds to this core issue.

Emotional/social and mental health examples

CORE ISSUE	EXAMPLES
Emotional / social and mental health	<p>Positive examples</p> <ul style="list-style-type: none"> + Using different means of communication to combat loneliness: social medias, video calls etc + Telehealth assisting those with psycho-social issues + Increased sense of community + Families spending more time together + As a patient, less infections due to confinement "healthier than I have ever been"

	Negative examples <ul style="list-style-type: none"> - Loneliness - Uncertainty about the future - Lack of empathetic /comforting “hugs” - Fear - Depression - Mental health issues - Isolation
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4.4 PID patients and COVID-19 education

As demonstrated in the previous section PID patients face additional concerns regarding core issues targeting the general public. Beyond this there are core issues specifically affecting patients with chronic diseases such as PIDs. One of these issues is COVID-19 education, the absence of which has posed a great challenge for patients during the past months. In many countries there has been a lack of national protocols within the health system that recognise the health needs of compromised patient groups, and concrete information for PID patients has been missing. Even though PID patient organisations all over the world have worked hard to provide their members with valid information, it has proven difficult to give guidance when the information is missing. In some regions there has even been conflicting guidelines in neighbouring countries, adding to the confusion for PID patients. With time more valid data and information is becoming available, but despite this many PID patients still ask the same questions as they did in March 2020, at the beginning of the pandemic, and this is a pressing issue that needs to be addressed.

PID patients and COVID-19 education examples

CORE ISSUE	EXAMPLES
PID community and COVID-19 education	Positive examples <ul style="list-style-type: none"> + More people are aware of immunoglobulin, plasma, antibodies and infectious diseases + More information streams available + Increased webinars for education + Using different media tools for awareness + Social media very important + NMO's step up their work for patients - finding new ways of communicating + More online meetings + More collaboration among patients + Patient groups more visible to general public + Crisis pushes patients to join patient groups + WPIW extension positive, gave more opportunities for patients to tell their stories + Great opportunity to increase number of plasma donors and donations + More understanding from family and friends + Immunologists work globally to address the issues of patients with PID who contract COVID-19 + Patient organisations globally sharing personal experiences of patients affected by COVID-19 + Social worker incorporated into patient group (Argentina)

- + More online meetings (Sweden, Australia)

Negative examples

- Zoom not always easy or accessible to everyone
- As a PID organisation, difficult to be heard and get through the “noise”
- Lack of patient registry makes information dissemination difficult
- Unproductive discussions between patients on social media (misinformation, “frenzy”)
- Different recommendations from different countries with the same language (patients don’t know what is correct)
- Absence of PID patient registry makes it difficult to locate patients in reference to their IG therapy
- Lack of specific information for patients
- Medical misunderstandings: “CVID” patients put in the “COVID-19” ward
- Hard to access care and medications
- Hospitals closed in some countries
- Trying to implement new-born screening for SCID made difficult as physical signatures need collecting and government only focused on COVID-19
- Difficult to raise awareness of PIDs (e.g. WPIW) as world is focused on COVID-19
- Lack of national protocols within the health system that recognise the health needs of compromised patient groups
- Governments and Public Health Authorities not enforcing COVID-19 pandemic rules to protect the vulnerable

4.5 Access to treatment

Other core issues affecting PID patients are access to treatment and health care systems. The pandemic and the lifestyle change it has brought has forced many PID patients to switch their treatments (e.g. from intravenous immunoglobulin to subcutaneous immunoglobulin that can be administered at home), or to switch between different brands of medication. There has also been signs of changes in patient behaviour such as stockpiling, leading to a local disruption in the medication supply. In some countries patients have not been able to attend their regular doctor’s appointments and have missed out on treatments (immunoglobulin, lung, physio etc) necessary for their wellbeing.

Access to treatment examples

CORE ISSUE	EXAMPLES
Access to treatment	Positive examples <ul style="list-style-type: none"> + Extension of WPIW gave more opportunities for patients to talk about their treatments + Raised awareness of blood donation + Opportunity to communicate with Ministry of Health for PID treatments, plasma collection (Argentina) + Home delivery of medicines (Canada) + Home treatment (Morocco) + Global efforts to develop treatments + Global efforts to develop vaccines

	<ul style="list-style-type: none"> + Joint effort of plasma industry to lead research
	Negative examples <ul style="list-style-type: none"> - Plasma shortage - Switching medication, not the same brand - Switching treatments - Going to hospital for treatment or to pick up product, risk of contamination - Changes in patient behaviour disrupting SCIG supply and leading to local tensions (Stockpiling medications, moving from cities to countryside) - Lack of adequate treatment model solutions for patients with PID and COVID-19 - Lack of therapies for patients - Access to mental health services and the stigma attached to it, despite a high increase in mental health needs - Dentist shut down - Difficult to visit medical specialists - Physio and lung treatments not available or disrupted

4.6 Healthcare systems and government

The COVID-19 pandemic has disrupted the hospital organisation and it is necessary to ensure that PID patients do not continue to suffer from this. On the plus side some countries have acted fast and offered PID patients home delivery of medicines and home treatments, despite it not being available before the pandemic. Telemedicine has also seen a great improvement in the past months. Despite these positive developments there are still many areas that need continued monitoring and improvement, one of them being a future plasma shortage that may affect PID patients in the years to come.

Healthcare systems and government examples

CORE ISSUE	EXAMPLES
Government and Healthcare systems	Positive examples <ul style="list-style-type: none"> + New home care systems have been established + Improved contact with physicians + More discussions with physicians + Specialists easier to contact through telemedicine + More contact with Ministry of Health may improve PID healthcare + More government focus on mental health and how to deal with it during the COVID-19 + Advances in telemedicine + Improved rural access to physicians through telehealth
	Negative examples <ul style="list-style-type: none"> - Governments and Public Health Authorities not providing enough information - Governments and Public Health Authorities not providing practical guidelines - Conflicts between Federal, State and Local government on COVID-19 guidelines and restrictions

- Governments and Public Health Authorities not enforcing COVID-19 pandemic rules to protect the vulnerable
- Telemedicine is difficult for some patients to adapt to (no physical contact, no examinations...)
- COVID-19 disrupts hospital systems (emergency department, planned surgeries, staff working hours and conditions, visiting hours etc)

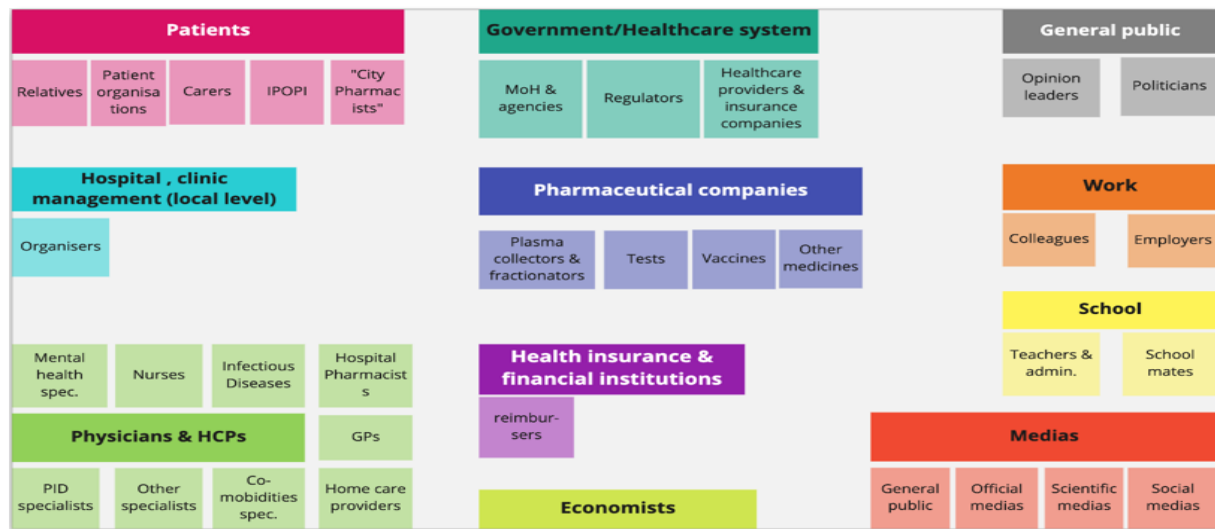
5.0 Disrupting patient access to stakeholders

The discussion with the participants also highlighted that the pandemic has caused a great disruption in the usual way patients access the diverse range of stakeholders.

5.1 Wide range of stakeholders in many fields

The groups defined the primary stakeholder categories as:

- Patients
- General public
- Physicians and Healthcare Professionals
- Government and Healthcare systems
- Pharmaceutical companies
- Work
- School
- Health insurance/Financial institutions
- Economists
- Medias & influencers



6.0 Key messages

To facilitate communication the LEX group defined a set of key messages, targeting the PID stakeholders as well as the previously discussed six core issues. Some key messages are suitable for more than one stakeholder category or core issue and may thus appear more than once.

6.1 Key messages for stakeholders

General public

- ☐ COVID-19 best practices: things to keep you safe during COVID-19 (masks, hygiene)
- ☐ Raise awareness of PIDs and vulnerability during COVID-19
- ☐ Recommendations for schools with PID patients/parents/siblings
- ☐ Patient community representatives need to know what to say and how to say it to the general community

PID community

- ☐ COVID-19 best practices: things to keep you safe during COVID-19 (masks, hygiene)
- ☐ Mental health – Promote options and support groups through PID organisation
- ☐ COVID-19 patient personal experience – sharing through the group
- ☐ Specific guidelines for immunocompromised patients
- ☐ Recommendations for schools
- ☐ Basic recommendations (masks, hygiene, isolation, schooling, work, keeping appointments, hospital access)
- ☐ More information to patients about their disease and disease pathway
- ☐ Access to information for newly diagnosed patients to be continued in usable formats
- ☐ Representatives from the patient community need to know what to say and how to say it

Healthcare professionals

- ☐ Immunologists should give advice, Netherlands good example of this
- ☐ Advice should be consistent nationally and globally
- ☐ Educate HCPs & governments on key issues (e.g. IG supply)
- ☐ Different HCP groups should agree on COVID-19 advice (align information between doctors and nurses)
- ☐ Recommendations for developing telehealth services (some patients are not benefitting due to costs or access)

Research

- ☐ Disseminate research outcomes
- ☐ PID patients to be included in studies
- ☐ Prioritize PID behaviour in COVID-19

- ☐ Access to global information

Healthcare systems

- ☐ Educate about PID
- ☐ Educate the vulnerability of PID patients
- ☐ State policy/framework for PID conditions
- ☐ Participation of Immunology Societies (by healthcare professionals & patients)
- ☐ Communication – diverse information – words not clarified, figures not explained, not put into context
- ☐ Explain cause of a second/third waves

Government

- ☐ Encourage more government supplied information about COVID-19
- ☐ Encourage increased governments cooperation when managing COVID-19
- ☐ Develop a series of pandemic recommendations that could be used to address policy
- ☐ Harmonise the rules (different countries have different guidelines)
- ☐ Establish specific protocols

Pharmaceutical industry

- ☐ Regular updates on vaccine progression
- ☐ Promote donation
- ☐ Promote need for post COVID-19 patient convalescent plasma donors
- ☐ Explain the difference plasma and convalescent plasma
- ☐ Data on plasma collection

School

- ☐ Guidelines (for parents, teachers & patients)
- ☐ Explanation of vulnerability of PID patients during COVID-19
- ☐ Alternative teaching methods for PID patients

Work

- ☐ Promote understanding of PID for flexibility in workplace

Health Insurance/Finance

- ☐ Effective health insurance coverage

Economists

- ☐ Cost of treatment
- ☐ Pharmacy
- ☐ Medicine costs increasing

6.2 Key messages for core issues

General public perception and behaviour

- ☐ Respect the rules
- ☐ Communicate PID patient experience with hygiene guidelines
- ☐ Communicate on decrease of infectious diseases linked to hygiene
- ☐ Communicate that even if you are well you can still have and transmit COVID-19
- ☐ Employers and co-workers must be responsible around PID patients

Emotional, Social and Mental health issues

- ☐ Mental health – Promote options and support groups through PID organisation

Lifestyle impact

- ☐ We are still in this together
- ☐ PID Be aware of risks – (e.g. education, schooling)

PID Patients and COVID-19 education

- ☐ COVID-19 best practices: things to keep you safe during COVID-19 (masks, hygiene)
- ☐ Mental health – Promote options and support groups through PID organisation
- ☐ COVID patient personal experience – sharing through the group

Access to treatment

- ☐ Ensure access to treatment
- ☐ Establish specific protocols
- ☐ Ensure supply
- ☐ Prevent tensions or shortages
- ☐ Maintain facilities given to some patients on accessing their treatments
- ☐ Follow up in local hospitals (or home)
- ☐ Prepare more for telehealth, telemedicine
- ☐ Facilitate home therapy

Healthcare systems

- ☐ Organise for rare conditions
- ☐ Establish pandemic procedures (hospital organisation, treatment delivery etc)
- ☐ Access to hospitals
- ☐ Access to treatment
- ☐ Good communication among specialists
- ☐ Promote early and regular communication
- ☐ Need a holistic approach
- ☐ Should include international specialist's communication
- ☐ Establish specific protocols for specific conditions

7.0 Recommendations: Focus areas for future action

To summarize the work of the IPOPI COVID-19 LEX team we have channelled the information into a set of six focus areas. These appear to be instrumental in the management of vulnerable people with rare conditions, such as primary immunodeficiencies, during a public health crisis. The goal with these focus areas and recommendations are to provide guidance and support for the work taking place during the current pandemic as well as for future possible similar scenarios. Importantly, these focus areas remain absolutely relevant in many countries even when there is no public health emergency.

7.1 Information on SARS-CoV-2, COVID-19

- Provide concrete information (contextualized)
- Harmonize local, regional, national and international information and guidelines
- Specific and comprehensive information to use by vulnerable people
- Specific and comprehensive information to use by other stakeholders: what they imply for the general public's behaviour, for HCPs' organisation

7.2 Communication

- Campaign on daily best practices
- Fight fake news and fake news activists

7.3 Organisation

- Adapt access to treatment and monitoring for vulnerable people with chronic treatment
- Adapt access to diagnosis and care to ensure no delays and to secure positive prognosis
- Adapt communication pathways for patients

7.4 Cooperation

- Promote research on the virus itself
- Multidisciplinary approach for working and organising, promoting holistic approaches
- Encourage cross border harmonized approaches (information sharing, clinics and research, data collection etc)

7.5 Innovation

- Develop new ways to organise (diagnosis, treatment, following up, including home treatment)
- Promote use of new technologies (artificial intelligence, telehealth/telemedicine)

7.6 Advocacy (human rights)

- Promote health coverage for chronic diseases in every country
- Ensure patients can continue to access their immunoglobulin therapy in an optimal manner, especially those with no alternative medicine such as PID patients
- Ensure an open and transparent dialogue with all stakeholders
- Ensure that appropriate action can be taken anticipatively, including demand management plan to allow prioritisation in case of tension

8.0 Taking action

8.1 12 - Step action plan template for NMOs

A simple 12 - step action plan template has been prepared for IPOPI's NMOs, based on the COVID-19 LEX Project. It is designed to be used in conjunction with the report to assist NMOs to take action and develop a project based on an appropriate focus area for their community during the COVID-19 pandemic.

The template aligns with the IPOPI COVID-19 LEX focus areas, strategies and recommendations developed.

The 12 steps include:

1. Core Issues (general and patient-specific)
2. Focus Area
3. IPOPI Recommendations
4. Stakeholders
5. Key Message
6. Project Team
7. Project Date(s)
8. Media format(s)
9. Resources required
10. Risk Rating
11. Results/report guideline
12. Continuous improvement

This 12 step action plan template guides NMOs through the project process, enabling them to develop a key message, target specific stakeholder(s), decide which media they will use to convey the message, what resources are needed, the budget, risk rating, results and continuous improvement.

The template can be used as a submission for IPOPI project funding as well as a project report and. It can be used by all NMOs, in all socio-economic regions.

IPOPI COVID-19 LEX PROJECT: 12 Step Action Plan: NMO Project Template.
This template will assist you in project planning during COVID-19, aligning with the IPOPI COVID-19 LEX Focus areas, strategies and recommendations developed in the COVID-19 LEX Report (tick boxes and complete blanks to develop your project).



1. CORE ISSUE(s): General <input type="checkbox"/> Public perception & behaviour <input type="checkbox"/> Lifestyle impact <input type="checkbox"/> Emotional /Social & Mental health		1. CORE ISSUE(s): Patient-specific <input type="checkbox"/> PID Patients & COVID-19 education <input type="checkbox"/> Access to treatment <input type="checkbox"/> Healthcare Systems	
2. FOCUS AREA(s) <input type="checkbox"/> 1. Information on SARS-COV-2, COVID-19 <input type="checkbox"/> 2. Communication <input type="checkbox"/> 3. Organisation <input type="checkbox"/> 4. Co-operation <input type="checkbox"/> 5. Innovation <input type="checkbox"/> 6. Advocacy		3. IPOPI RECOMMENDATIONS <input type="checkbox"/> Provide concrete information (contextualized) <input type="checkbox"/> Harmonize local, regional, national and international information and guidelines <input type="checkbox"/> Specific and comprehensive information to use by vulnerable people <input type="checkbox"/> Specific and comprehensive information to use by other stakeholders: what they imply for the general public's behaviour, for HCPs' organisation <input type="checkbox"/> Campaign on daily best practices <input type="checkbox"/> Fight fake news and activists <input type="checkbox"/> Adapt access to treatment and monitoring for vulnerable people with chronic treatment <input type="checkbox"/> Adapt access to diagnosis and care to ensure no delays and to secure positive prognosis <input type="checkbox"/> Adapt communication pathways for patients <input type="checkbox"/> Promote research on the virus itself <input type="checkbox"/> Multidisciplinary approach for working and organising, promoting holistic approaches <input type="checkbox"/> Encourage cross border harmonized approaches (information sharing, clinics and research, data collection etc) <input type="checkbox"/> Develop new ways to organise (diagnosis, treatment, following up, including home treatment) <input type="checkbox"/> Promote use of new technologies (AI, telehealth, telemedicine) <input type="checkbox"/> Promote health coverage for chronic diseases in every country <input type="checkbox"/> Ensure patients can continue to access their immunoglobulin therapy in an optimal manner, especially those with no alternative medicine such as PID patients <input type="checkbox"/> Ensure an open and transparent dialogue with all stakeholders <input type="checkbox"/> Ensure that appropriate action can be taken anticipatively, including demand management plan to allow prioritisation in case of tension	
4. STAKEHOLDER(s) <input type="checkbox"/> Patients/ PID community <input type="checkbox"/> Government/ Healthcare systems <input type="checkbox"/> General public <input type="checkbox"/> Industry (pharma) <input type="checkbox"/> Insurance /Finance <input type="checkbox"/> Healthcare professionals <input type="checkbox"/> School <input type="checkbox"/> Work <input type="checkbox"/> Economics			
5. KEY MESSAGE: <i>What key message you want to convey?</i>			
6. PROJECT LEADER: _____			
PROJECT TEAM: _____			

7. PROJECT DATE(S):			
8. MEDIA FORMAT(s)			
WRITTEN <input type="checkbox"/> Letter to authorities <input type="checkbox"/> Position statement <input type="checkbox"/> Call to action <input type="checkbox"/> Research <input type="checkbox"/> Guidelines & recommendations <input type="checkbox"/> Templates for NMOs <input type="checkbox"/> Infographics <input type="checkbox"/> Pamphlets <input type="checkbox"/> Posters	<input type="checkbox"/> Articles <input type="checkbox"/> Poster presentation <input type="checkbox"/> Abstract for Congresses <input type="checkbox"/> Quizzes <input type="checkbox"/> Animation <input type="checkbox"/> Cartoons & sketches <input type="checkbox"/> Children's storybook	VERBAL <input type="checkbox"/> Roundtable discussions <input type="checkbox"/> Presentations <input type="checkbox"/> Patient interviews & stories	TECHNOLOGICAL <input type="checkbox"/> Website information <input type="checkbox"/> Social media <input type="checkbox"/> Facebook <input type="checkbox"/> Twitter <input type="checkbox"/> Instagram <input type="checkbox"/> LinkedIn <input type="checkbox"/> Email <input type="checkbox"/> E-newsletter <input type="checkbox"/> Webinars <input type="checkbox"/> Podcasts <input type="checkbox"/> Live streaming
9. RESOURCES REQUIRED			
<input type="checkbox"/> People - <i>Who is required?</i>			
<input type="checkbox"/> Finance - <i>How much will it cost?</i>			
<input type="checkbox"/> Materials - <i>What do you need?</i>			
<input type="checkbox"/> Information - <i>What data/info do you need?</i>			
<input type="checkbox"/> Services - <i>What services do you need?</i>			
<input type="checkbox"/> Equipment - <i>What items do you need?</i>			
10. RISK RATING: <input type="checkbox"/> LOW <input type="checkbox"/> MED-LOW <input type="checkbox"/> MEDIUM <input type="checkbox"/> MED-HIGH <input type="checkbox"/> HIGH			
11. RESULTS / REPORT GUIDELINE			
<input type="checkbox"/> Has your project been successful?			
<input type="checkbox"/> What was your message?			
<input type="checkbox"/> What did you do?			
<input type="checkbox"/> How did you do it?			
<input type="checkbox"/> Was the project cost effective?			
<input type="checkbox"/> How have you measured the success of your project?			
12. CONTINUOUS IMPROVEMENT			
<input type="checkbox"/> What concerns did you have during the project?			
<input type="checkbox"/> Is there anything you would have done differently?			

9.0 Concluding remarks

The aim of IPOPI's COVID-19 Learning Expedition was to identify, analyse and provide recommendations on issues brought about by the COVID-19 pandemic for PID patients. The input from the participants of this project has clearly highlighted the double burden faced by PID patients during these past months. The experiences show that PID patients are not only affected more than the average citizen by matters concerning the general public, but also weighed down by additional issues specifically targeting PID patients. The extra vulnerability this creates is something vitally important to address when discussing the effects of this pandemic for PID patients, and it is something we believe to have done in this report. Lastly, the overall purpose of the LEX project, and in turn of this report, has been to assist our global PID community when coping with this health crisis. We hope and believe that this report will support and guide our members when doing so.

Appendices

1.0 Media formats

Beyond discussing core issues, stakeholders, key messages and focus areas the LEX team has also worked on the possibilities for communication of these outcomes. Below is a wide selection of actions and tools to support this communication.



1.1 Spotlight on digital medias

Webinars

- Webinars to unite PID community
- Continue global webinars

Social media

- Promote examples of positive developments globally
- Promote discussion topics
- Use underlying principles of uniting patients globally to reduce fear and promote support
- Promote topics affecting patients – plasma, immunoglobulins, mental health
- Promote the “right” information
- Gathering data

2.0 Support tools for patient representatives

2.1 Risk Analysis Framework

- To assist patients in decision making (red, yellow, green – stoplight model)
- Transparency to incorporate different stakeholders in decision making (IG supply, plasma collection, vaccines)

Low	Med-Low	Medium	Med-High	High
<ul style="list-style-type: none"> • Online • Home office 	<ul style="list-style-type: none"> • In office • PPE • Observe social distancing • Travel in own car • 2-3 people 	<ul style="list-style-type: none"> • Meeting outside • PPE • Observe social distancing • Travel in own car • Up to 4 people 	<ul style="list-style-type: none"> • Involves meeting in a restaurant • Involves public travel • More than 6 people 	<ul style="list-style-type: none"> • Face to face • In community • Involves public travel • More than 10 people

2.4 PID patient personas

The LEX team has also provided personas who can be of great help in defining typologies of PID patients in the context of a pandemic, to consider optimal ways of supporting them.

PERSONA

Characterise a typical person with PID facing COVID-19. Not an existing one, but one who represents a prototype who you've met in your patient organisation.

Short description: Geoff was diagnosed in his teens with CVID, he has been relatively well since starting immunoglobulin therapy in 1970's. He has been able to work full time, lives with his partner and has no children.

Photo or drawing of persona	First name	Age	Nationality	Town
	Geoff	57	Australian	Sydney
	Family	Job	Hobbies	Studies
		IT	Fishing, travel, photography	Masters IT, UTS

Pains

Due to COVID, Geoff has concerns about going into the hospital to receive his IVIg, he has heard about SCIg but his immunologist has never mentioned it and now he thinks it might be a good idea for him to try. Unfortunately, the product is not available to him and he would have to go to a different hospital to access it. During lockdown and fearing exposure, Geoff decided to not go to get treatment and that he would be safer at home – unfortunately, this left him vulnerable and he ended up with a chest infection requiring hospitalisation.

Needs

Better access to treatment, or information about treatment management during a pandemic.

Goals

To find a way to get access to SCIg without having to change hospitals or immunologists. to have more information about the right ways to stay safe during a pandemic

Dreams

To remain healthy, to be more in control of my treatment, to have access to available and affordable treatments

Expectations to stakeholders

Geoff would like more information for people like him who want to self isolate but need access to immunoglobulin.

What does she/he say? (a quote)

« If the SCIg product was available for me, I would feel safer at home. I think I made the wrong decision not going to hospital for my treatment but I was scared to go in there, I didn't know what to do »

What does she/he think? (main ideas)

Geoff is trying to make a decision on whether it's worth changing healthcare so he can have access to the SCIg product so he can feel safe isolating at home.

What does she/he do? (main actions)

After talking with his doctor, he decided it was more risk to not have treatment, and so he is hesitantly going to hospital again.

How does she/he feel? (main feelings)

He is anxious and frustrated. Each time he goes to the hospital it's a fearful time.

Preferred channels / devices for interaction

Face to face Phone Computer Smartphone/tablet Mail (Instant) messaging Social medias

PERSONA Characterise a typical person with PID facing COVID-19. Not an existing one, but one who represents a prototype who you've met in your patient organisation.

Short description <i>Shelly</i>				
Photo or drawing of persona	First name	Age	Nationality	Town
	<i>Shelly</i>	<i>65</i>	<i>Canadian</i>	
	Family <ul style="list-style-type: none"> <i>Husband</i> <i>2 adult daughters, one of which has a 4 year son and 18 month old daughter</i> 	Job <i>Retired teacher</i>	Hobbies <i>Gardening</i> <i>Hiking</i> <i>Walking the dog</i>	Studies <i>n/a</i>
Pains <ul style="list-style-type: none"> <i>Some arthritis in her hands and knees</i> <i>Environmental allergies that are really acting up this season</i> 				
Needs <ul style="list-style-type: none"> <i>Follow ups with specialist at 6 month intervals</i> <i>SubQ treatments 1x/week</i> 				
Goals <ul style="list-style-type: none"> <i>Be there for her daughters, and as a grandmother (although she cannot babysit with COVID)</i> 				
Dreams <ul style="list-style-type: none"> <i>Family camping trips when the grandkids are old enough</i> <i>Has been wanting to do a trip to Scotland to celebrate their retirement</i> 				
Expectations to stakeholders <ul style="list-style-type: none"> <i>Government: Implement more messaging around controlling risk with COVID so that more people will respect social distancing and wear masks</i> <i>Health care team: understand personal immunodeficiency issues and what she can or cannot risk, provide some guidance (can she safely see her children and grandchildren? What about when school starts again?)</i> 				
What does she/he say? (a quote) <i>It is what it is.</i>		What does she/he think? (main ideas) <ul style="list-style-type: none"> <i>Thinks the government directives are confusing (too much conflicting mandates)</i> 		
What does she/he do? (main actions) <ul style="list-style-type: none"> <i>Hand sanitizes/washes hands often, wears a mask out in public</i> <i>Stays home and tries to keep busy</i> <i>Has video calls her daughters and grandkids</i> 		How does she/he feel? (main feelings) <ul style="list-style-type: none"> <i>Sad for only seeing her children and grandchildren at a distance</i> <i>Confused about how to navigate risks (like grocery shopping, pharmacy visits)</i> <i>Starting to tire of the isolation and the need to always be aware of risk</i> 		
Preferred channels / devices for interaction Face to face <i>Phone</i> <i>Computer</i> <i>Smartphone/tablet</i> Mail (Instant) messaging Social medias				

PERSONA

Characterise a typical person with PID facing COVID-19. Not an existing one, but one who represents a prototype who you've met in your patient organisation.

Short description: India has Specific Antibody Deficiency, moved from her small country town in South Australia to Melbourne seeking more work opportunities and to be closer to her bandmate, they played gigs around Melbourne. Because of COVID she's had to move back home.				
Photo or drawing of persona	First name	Age	Nationality	Town
	India	22	Australian	
	Family	Job Barista	Hobbies Music, art, coffee, plants	Studies Currently studying bachelor Environmental Studies
Pains Has been so terrified in Melbourne, got an expetion to move back home with family. She's eperienced many hospitalised due to pnunomia and chest infections relating to SAD in the past, and because the only treatment for her right now is antibiotics, she's worried she would not survive if she caught the COVID virus. She said she feels like her life was just beginning and now everything has been taken away from her.				
Needs Respiratory and immunology specialists, continued Antibitics prophylaxis, mental health support to cope with changes				
Goals For the pandemic to be over so she can return to Melbourne and get back to 'living'. To get access to mental health services because she's not coping with all the changes. The fear that this might be the way things are for a long time makes her angry, like she's missing out, she'd like support in adjusting to the changes.				
Dreams For venues to reopen so she can play at gigs again, to hang out with friends. To stay mentally healthy				
Expectations to stakeholders Please focus your energies on making a vaccine				
What does she/he say? (a quote) »it sucks because I feel like my life was just beggining, now I'm back home, back with parents, and my whole life has been put on hold. It sucks because I literally had to choose between my physical or mental health, and I chose physical thinking I could tough it out, but its really hard.		What does she/he think? (main ideas) She thinks its the absolute pits. She wonders if she'll ever get to hug her firends again		
What does she/he do? (main actions) Stays home, she doesnt have a job anymore, she can still study online so thats keeping her busy. She keeps in touch with her friends in melbourne via Zoom		How does she/he feel? (main feelings) Angry! Frustrated! She says moving home was the right thing to do, doesnt mean it was the happiest thing to do.		
Preferred channels / devices for interaction Face to face Phone Computer Smartphone/tablet Mail (Instant) messaging <u>Social medias</u>				

PERSONA Characterise a typical person with PID facing COVID-19. Not an existing one, but one who represents a kind of prototype who you've met in your patient organisation.

<p>Short description Kyle is an American high school student living with XLA. His grandpa and uncle both died of XLA before it was well diagnosed so he gets the seriousness of his disease. But it is hard sometimes – especiall with school closing and no extracurricular activities.</p>				
	<p>First name Kyle</p>	<p>Age 16</p>	<p>Nationality United States of America</p>	<p>Town</p>
	<p>Family Mom, Dad and younger sister (age 15)</p>	<p>Job Summer 2019 worked as a tennis camp coach; 2020 camps closed.</p>	<p>Hobbies Tennis, Robotics Team, Fishing, Mixed Choir (through school)</p>	<p>Studies High School with IB / Advanced Placement courses</p>
<p>Pains I'm very selective about who I share my health story with and about my weekly infusions so I feel that even some of my very good friends don't know about ALL of me. I've lost some friends who just think COVID is all a hoax and stuff.</p>				
<p>Needs I need my parents to give me some space to make my own decisions. I'm going off to college soon and they've taught me good values and know I'm a good student ... but they have always been more 'active' in the parenting department than my friends' parents.</p>				
<p>Goals Graduate from high school with honors and an IB diploma. Get accepted to a highly recognized engineering undergraduate program.</p>				
<p>Dreams Earn a degree in mechanical or industrial engineering. Get a job that has really good insurance (what 16 year old says that!) and work with smart people who respect me.</p>				
<p>Expectations to stakeholders Stakeholders – What do you mean? Like my parents?</p>				
<p>What does she/he say? (a quote) 'Work hard. Dream big.' 'Life can suck some time but NOT all the time'</p> <p>Do you know all the things I wish I could say to my friends....sometimes they don't know how good they have it when they never get sick!</p>		<p>What does she/he think? (main ideas) Life is hard some times. I've been through some rough patches but the good thing is I've come through them. I think I've learned to balance being independent with depending on others. There are some people in this world that don't know how good they have it!</p>		
<p>What does she/he do? (main actions) Stay focused on school. Play online games to keep in touch with friends (because my mom is not too sure if tennis is 'safe' – IT IS MOM!) Keep up with those infusions even though I've started to wish I did not have to keep doing them – when will there just be a pill I can take?!?!?</p>		<p>How does she/he feel? (main feelings) Optimistic about the future. I miss my choir friends – we've gone on some cool trips to sing at the Rockets basketball game and the MLB All Star game! Confident in school work and my academic success. Isolated at times and lonely particularly during the pandemic. Sad that I've lost some friends who think this is all a 'pandemic.'</p>		
<p>Preferred channels / devices for interaction Face to face Phone Computer Smartphone/tablet Mail (Instant) messaging Social medias</p>				

PERSONA Characterise a typical person with PID facing COVID-19. Not an existing one, but one who represents a prototype who you've met in your patient organisation.

Short description: Due to a late diagnosis of CVID and recurrent infections, Belinda has bronchiectasis, bowel disease and sinusitis. She also has Autoimmune conditions. She lives at home with her husband and two sons.

Photo or drawing of persona	First name	Age	Nationality	Town
	Belinda	43	Australian	
	Family	Job	Hobbies	Studies
		Unable to work	Cross-stitch, gardening, spending time	Bachelor of Arts

Pains

Due to COVID – reduced therapies have been hard, not being able to use the hydrotherapy pool or physio has had an impact on health management. She's also anxious everytime she has to go in to hospital for any reason. She's about her kids at school bringing the virus home.

Needs

Due to COVID she needs telehealth consultations when possible, pharmacy to car service for collecting SCIg and medications, access to online delivery for groceries, healthcare in the home to wear masks and gloves, the school to notify her immediately of any outbreaks, to avoid public areas like shopping centres. Access to informat-

Goals

For the general public to listen to the advice of scientists and health professionals and wear masks, wash and sanitise hands regularly, stay home when sick. Her personal goal is to minimise the risk of having to go to hospital

Dreams

That even when the Covid pandemic is over, people will remain empathetic about people with immunodeficiencies who have to live this way all the time.
That she can feel safe again.

Expectations to stakeholders.

To work on finding ways for people with immunodeficiency to keep safe during the pandemic, to provide her with information on COVID

What does she/he say? (a quote)

« For you this (isolation) is temporary, for me this is lifelong »

What does she/he think? (main ideas)

She thinks that many people increasing handwashing, wearing masks, and isolating has been beneficial to people like her, and hopes the standard of hygiene continues even after the pandemic is over

What does she/he do? (main actions)

Belinda stays home and isolates as much as possible, when her husband and children get home, they shower straight away and put their clothes in the washing machine, the whole family contributes to keeping Belinda safe.

How does she/he feel? (main feelings)

She feels anxiety about getting COVID, as she's been hospitalised with pneumonia often due to immunodeficiency. She knows how scary and deadly a virus can be to the immunocompromised.

Preferred channels / devices for interaction

Face to face Phone Computer Smartphone/tablet Mail (Instant) messaging Social medias

PERSONA

Characterize a typical person with PID facing COVID-19, not an existing one, but one who represents a kind of prototype who you've met in your patient organisation.

Of course you can imagine several personas as several types do exist, then use several sheets.

Short description A persona who is very unsure about how to handle this pandemic. Especially since she is working in a room filled with other people (classroom), while also having a child at home with PID.				
Photo or drawing of persona	First name	Age	Nationality	Town
	Anna	38	Sweden	
	Family	Job	Hobbies	Studies
	Husband and 3 children	Teacher	Enjoy nature and reading	
Pains Anna doesn't know how to adapt to her new life in the pandemic. She has to work as a teacher and meet all of her students every day, but she also has a child at home in a risk group (PID). She is afraid she will bring COVID-19 home to her child.				
Needs Some guidelines on how to think about this issue and to minimise the risk of her bringing home COVID-19 to her family and PID child.				
Goals to keep her family, and especially her child with PID safe during this pandemic. That means both being able to earn money and to not bring COVID-19 back home from work.				
Dreams Keep the family healthy, while also being able to earn a salary from her teachers job.				
Expectations to stakeholders To make sure the "weakest" (risk groups) in this pandemic are taken care of in a safe way.				
What does she/he say? (a quote) "Honestly I dont know how to act in this issue and I'm positive that i'm far from the only one struggling with this. We need some common PID guidelines"		What does she/he think? (main ideas) The guidelines for how to stay safe in the pandemic as a PID patient are too few. Recommendations that fit most PIDs should be developed.		
What does she/he do? (main actions) Following recommended guidelines such as washing hands often, using hand sanitizer, reminding her students about this as well.		How does she/he feel? (main feelings) Frustrated, because she don't know what to do or how to act.		
Preferred channels / devices for interaction				
Face to face	Phone	Computer	Smartphone/tablet	Mail
	X	X		X
				(Instant) messaging
				X
				Social medias
				X

PERSONA

Characterise a typical person with PID facing COVID-19. Not an existing one, but one who represents a prototype who you've met in your patient organisation.

Short description Eva was diagnosed 4 years ago with Hypogammaglobulinaemia and is on weekly SCIg infusions. Her Dad, Mark, is the main carer in her healthcare. She has two older brothers and lives on a rural property with horses, Gerry the alpaca, two dogs a cat and chickens.

Photo or drawing of persona	First name Eva	Age 13	Nationality Australian	Town
	Family	Job N/A	Hobbies Snapchat, drawing, swimming, taking care of my animals	Studies In year 7

Pains

Not being able to see her friends as much. Her dad 'making a huge fuss' about things like school, friends parties, etc.
Having to have needles and going into hospital

Needs

Weekly SCIg Infusions, product can be picked up at local hospital pharmacy. Eva goes to Sydney to see her immunologist when needed. Eva needs awareness about her immunodeficiency at school, so there can be support for when she needs to isolate at home.

Goals

For dad to be less stressed, everytime she has a sniffle he panics and the whole house is mayhem. He is constantly checking the news to see where the outbreaks are happening. She would like him to have more support.

Dreams

« getting my treatment without needles! » She says she doesnt mind too much the time off school, she likes spending time at home, she does miss things like parties, at the moment, her dad wont let her go to any, even though the restrictions arent as tough at the moment. If she could attend a party safely without anyone stressing she'd be happy

Expectations to stakeholders: working on ways to help keep her dad informed and ways he could access supports. A helpline he could call when he doesnt know what to do.

What does she/he say? (a quote)

« it sucks not being able to go to parties or hang out with friends. its not so bad at the moment cuz my friends know a bit more about the immune system and viruses, it was hard trying to explain what was wrong with me when I was diagnosed. »

What does she/he think? (main ideas)

While it sucks having to hang out with her brothers a lot, she still feels like the pandemic has brought the family closer together. Her brothers have been showing a protective side which she's enjoyed. She also likes that her brother taught himself how to bake during the first lockdown

What does she/he do? (main actions)

Hygiene has increased in the home and the whole family has taken extra care in isolating as much as possible.

How does she/he feel? (main feelings)

She feels ok, she's quite a level headed teen and can see the positives in a lot of things, she mainly worries about her dads anxiety.,

Preferred channels / devices for interaction

Face to face Phone Computer Smartphone/tablet Mail (Instant) messaging Social medias

PERSONA

Characterise a typical person with PID facing COVID-19. Not an existing one, but one who represents a prototype who you've met in your patient organisation.

Short description: Margaret was diagnosed with CVID in her 60's, she knew she was always more sick than others but just 'got on with things'. She started on IVIg and moved to SCIg a year ago. She has many comorbidities but that doesn't stop her living life to the fullest. She lives alone. She has a huge family (5 children, 8 grandchildren and 2 great grandchildren) and had a huge social life, it's been hard adjusting.

Photo or drawing of persona	First name Margaret	Age 71	Nationality Australian	Town
	Family	Job Retired	Hobbies Quilting, bowls, spending time with grandkids	Studies

Pains

Due to COVID, much of Margaret's social life has been taken away. Even though she lives alone, the house was usually always busy with friends and family stopping in. She misses playing bowls with her friends and having people over.

Needs

Since her family have been around less, she has needed more care at home – she also needs way to communicate with her family and friends safely. She might need help with administering her own SCIg, even though she can do it on her own, she preferred when someone was with her just in case things went wrong

Goals

To find ways to stay in touch with my friends and family, to keep active and maintain my health while at home
To stay independent

Dreams

To hug my family members again, to be there for them and all my grand and great grandchildren.
To go back to bowls! There's only so much time during the day I can spend quilting.

Expectations to stakeholders

To assist with any research in finding a vaccine. To keep me and my family informed about the COVID virus and ways to stay safe

What does she/he say? (a quote)

« I miss holding my family, I miss the business of the house of a neighbour popping in for tea or the whole family coming for Sunday lunch »

What does she/he think? (main ideas)

I think it's frustrating when I see people not wearing masks, or people who think this is a joke. Especially young people, you might survive the virus, but I won't.

What does she/he do? (main actions)

I keep myself as safe as possible by staying home. I know I'm vulnerable. I try to stay active by walking around my garden and I try to stay connected by Facebook

How does she/he feel? (main feelings)

I feel lonely but also we have to be pragmatic about these things. World Catastrophies are not new to me, to be honest I'm glad it's a pandemic and not a War

Preferred channels / devices for interaction

Face to face Phone Computer Smartphone/tablet Mail (Instant) messaging Social medias