



Position Paper January 2022

Background

The Malta Health Network (MHN) is an umbrella organisation which brings together health related organisations. The MHN was set-up in 2007 with 17 member organisations, in 2022 it represents 40 member organisations (complete list of members attached), amounting to representation of over 12,000 families.

MHN strives to give patients an informed voice in health-related matters in Malta, in the EU and internationally. The main objectives of MHN are patient empowerment, patient advocacy and training, and also aims at providing an efficient platform where all our members can network and achieve common goals through sharing of resources. MHN is affiliated with various European and International organisations and is regarded with high esteem amongst these groups. Over the years we have been involved in various initiatives and partnered in several projects involving patient empowerment, education, and advocacy.

MHN promotes the health-related interests of patients and the wider community by updating itself about international 'best practices' and 'capacity-building'. The MHN achieves this through its regular contacts with local and international health-related Governmental Organisations, Non-Governmental Organisations, 'Not-for-Profit' Organisations and Patient Representative Groups. Since its establishment in 2007, MHN has carried out several projects with an aim to improve the Maltese healthcare scenario.

The MHN is independent of the Government of Malta and of any political party or organization. Amongst our present priorities for the health sector are:

- Patients' Rights in Health Legislation: Since 2008 MHN was the first entity to start speaking on Patients' Rights in Malta. MHN is very satisfied that, by 2014, two critical legislative enactments in the sector of health were fully operational and the launch of the Patients' Charter is another step we favour. However, we want to see this strengthened through legally binding, appeal mechanisms applicable to both public and private health services.
- Patients' Rights in Cross Border Directive: The Health Act, enacted in October 2013, had applied Patients' Rights in the Cross Border Health Care of the EU Directive. MHN pro-actively promoted this Directive, holding a series of educational seminars locally regarding the Rights enjoyed by patients as a result of this Directive. MHN has a positive rapport with the National Contact Point and though we are not closely involved in how the process has worked over the past years we want to keep increasing the national awareness and implementation of this Directive so that more patients can benefit from the rights derived from the directive.
- Addressing Chronic Pain on a National level. MHN in collaboration with Societal Impact of Pain Europe organised the international symposium during Malta's presidency of the Council of Europe in 2017. MHN was the first entity in Malta to carry out original research using validated tools on Chronic Pain and contributed by providing data and recommendations. MHN remains committed to advancing this issue.
- Health & Environment: On a European level, MHN has favoured campaigns promoting patient safety and fighting antimicrobial resistance. The health sector is inevitably impacted by the environment thus we demand better environment management solutions for an improved air quality and controlled use of antibiotics in farming which could save both yearly premature deaths and reduce health costs.
- Removing barriers encountered by Maltese 'patients' when trying to access life-insurances. MHN had long been campaigning in this area and contributed to the recently launched scheme 'A new hope' guarantee scheme by the Ministry for social accommodation and Ministry for social wellbeing and inclusion. As MHN we are still committed to continue supporting this scheme through our representation on the appointed board, but we would like to see this scheme expanded and consolidated to reflect today's reality.
- During the past 2 years of the Pandemic MHN together with our member SOS Malta we have managed over 600 volunteers to support the work of the health authorities. In 2020 we supported public health in the helpline, contact tracing and other duties whilst in 2021 we have supported extensively in the vaccination services. We would like to keep this volunteer pool for possible future needs and projects.
- We have been promoting to have better representation of Maltese patients on regulatory bodies.

Malta Health Network

Postal address: PO Box 2, Qormi Rd., Marsa MRS1000, Malta

Tel: +356 99873213

www.maltahealthnetwork.org - info@maltahealthnetwork.org

Current Focus:

More recently members wanted to highlight their increasing problems when trying to access medicines and services, and after numerous consultations we are reporting a summary of our findings here.

Access to medicines:

1. It appears that the normal medicines which are taken for some conditions are sometimes unavailable or changed to a different brand of medicine. As a result, some patients found this new medicine to be not as effective as their normal/original medication.
2. Some patients were switched from biological medicine to biosimilar medicine and in most cases the consultants were not even informed of these changes. The new medicine which is supposedly to be cheaper to produce was deemed just as effective. However, some patients were negatively affected whilst others were ok with this change.
3. A critical issue is that patients appear to have **no voice, no choice and no patient centred care**. This is because the procurement procedure leaves no space for the needs of the patient to be considered as its only aim is to buy cheaper medicine on the market.
4. Access to tele-medicine was provided during COVID, and members would like to retain that option even after COVID related measures are lifted.
5. The need for information to be given to patients was highlighted.
6. There are situations where the patients have had to resort to the Malta Community Chest fund for their critical medicine which is very costly to buy and not provided to them by the Govt. This practice is considered as reducing patients to beggars.

Our recommendations to the above-mentioned issues:

a) There should be an emphasis to have a **real patient representative** on the Health Council as required by law and patient representatives sit on the different health & entitlement committees even if not explicitly required by law. This would lead to a more patient-centred care and better representation of the Maltese patient.

b) **Dignity** does matter. This necessitates health care which puts the patient at the center of care, a holistic consideration of the patient and significant others.

c) Better patient-doctor/health professional **communication**. Patients want to be informed better of medicine choices, side-effects etc to be involved in decision making process about their medication.

d) On the issue of Biosimilars and generic: A possible solution to this problem can be the introduction of a **part payment** by the patient. i.e., the patient will fork out a small percentage of the cost in order to retain the biologic medication which s/he was taking if s/he does not find the biosimilar as effective. Considering the fact of co-financing, treatment to be considered on a patient-to-patient basis, not too bureaucratic and also takes care of patient health situation & responsibilities of carers.

e) Publicly accessible **guidelines** and pathways guiding medical professionals. Treatment should be based on informed decision process in conjunction between patient and the responsible consultant, based on facts and standard operating procedures.

f) Entitlement to medicines should be uniform and unequivocal. Medicines which are free for particular conditions but not for others, e.g. epilepsy medication which helps persons with Schizophrenia. Medicines should be equally accessible irrespective of condition.

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- g) Revision of amount of entitlement through vouchers to reflect the increase in cost of buying such products and regular revisions to include any other products available on the local market.
- h) Changes to the **medicines entitlement** system & formulary needs to be revised with active patients/patient representative involvement. Innovative medicines need to be considered in a timely manner.
- i) **Telemedicine** services which have developed over the past months need to be reviewed as a positive step forward and kept in service delivery. Community services are welcomed by patients as often these prevent the need for acute or secondary services including hospitalisations.

Another issue is access to therapeutic services. From our consultations it transpired that:

- 1) Treatment given to patients depends very much on the consultant and how much he pushes for this treatment to be administered. It is being felt that access to treatment is not uniform for all patients.
- 2) There is a long waiting list for some services e.g., psychotherapy and physiotherapy. Some NGOs are trying to help out with these services; however, they have very limited resources.
- 3) Free psychotherapy and physiotherapy sessions are capped at 10 sessions only.
- 4) There is a need for a Rehabilitation Centre so that all these essential services (e.g. psychotherapy, physiotherapy etc) will be available under one roof.
- 5) It is time that a Joint Declaration on the recognition of Mental Health problems as a Disability is presented to the government and be acted upon. This would address the anomaly that mentally ill persons who apply to be boarded out or for disability benefits are not considered entitled for such support. People are advised to approach the Lino Spiteri Foundation to be helped to find a job even though they have tried and failed on their own several times. However, the Lino Spiteri Foundation is geared to assist persons with a disability not persons with mental health problems and so at times this attempt fails too leading to more worsening of the mental health situation.
- 6) The needs of family Caregivers of mentally ill persons, need to be urgently addressed.
- 7) Young carers: the Ministry of Health and the Ministry of Education need to urgently collaborate to come up with a support programme for Young Carers – adolescents and teenagers who care for a relative with an addiction problem, a mental health difficulty, a disability, encroaching dementia, terminal illness etc. These Young Carers would benefit from live-ins, summer programmes, weekend activities which enable them to have some respite.
- 8) Social Assistance ('relief'): Persons suffering from a mental illness can only qualify for welfare benefits (SA) *IF* they live separately from their parents. This is creating more pressures on the social accommodation system, on the mentally ill persons themselves who need much support to live independently and to manage their meagre income.

Our proposed Recommendations in this regard are:

1. Access to rehabilitation and therapeutic services should have a reasonable waiting time.
2. Better information on therapeutic options available instead of or to compliment medication. This may include dietary changes, physical activity etc. Persons may need support to access these eg vouchers to pay for gym membership instead of being given free medicines.
3. Proper prevention programmes throughout the life to prevent non-communicable disease such as obesity, heart conditions etc. broader preventative screening and early diagnosing programmes to proactively tackle problems in a timely manner.
4. Therapeutic services e.g., Counselling services, physiotherapy sessions and psychotherapy sessions should not be capped. Some services are being given by NGOs who charge patients for some services when they exceed the number of 'free' sessions this is discriminatory on poor often more needy patients.
5. More specialised centres that cater for patients with mental health issues in the community that treat the patient holistically and not just the disease, and specialised clinic for caregivers like the one SJAF runs but with a team in place.
6. Persons with severe mental illness who live with their parents or are being taken care of by siblings in the community should have access to Social Assistance and not just sickness benefits.
7. Young carers: there should be inter-ministerial collaboration to provide support programme/s for Young Carers – adolescents and teenagers who care for a relative with disabling health conditions such as addictions, mental health difficulties, physical disabilities, dementia, terminal illness etc. this should enable them to have some respite and build networks.

Conclusion

MHN hopes to continue working with all interested bodies and stakeholders in a meaningful way to ensure that the voice of patients is included and reflected in decisions taken right from the beginning of the concept development of any policies or changes to current practices. This will lead to have the best health service and health policies the Maltese citizen truly deserves.

We hope to be given the opportunity to utilise our vast resources in a meaningful way, so as to maximise the potential we can achieve as a health platform.

We would also like to offer our support and expertise especially with regards of experiences of our member organisations.

We believe that health is holistic and thus cannot be tackled in isolation – we recommend that policies related to environment, work practices and social services should take health in consideration due to the impact of these measures on the health of society in general.

We see the need in our society to have more evidence based and investment in local research so that decisions reflect the real needs of our society.

As at 2022, the MHN members are:

Action for Breast Cancer Foundation
ADHD Malta
Arthritis & Rheumatism Association Malta
Ass. of Occupational Therapists
Ass. of Speech Language Pathologists
Beating Hearts
Carita Malta Epilepsy Association
Coeliac Association Malta
Crohn's and Colitis
Europa Donna Malta
Friends of Attard Hospital Society MCH
Friends of the Sick & the Elderly in Gozo
Genetics and Genomic Counselling Association-Malta
GS1
Home Economics in Action
Karl Vella Foundation
Lumier Support Group
Malta Association of Physiotherapists
Malta Association of Public Health Medicine
Malta Chambers of Pharmacy
Malta Chiropractice & Chiropractic Association
Malta Cochlear Implant Association
Malta Colorectal Cancer Group
Malta Dementia Society
Malta Diabetes Association
Malta Eczema Society
Malta Heart Foundation
Malta Hospice Movement
Malta Medical Student Association
Malta Obesity Association
Malta Osteoporosis Society
Multiple Sclerosis Society Malta
Nanniet Malta Foundation
National Association of Pensioners
National Ass. of Rare Diseases
Richmond Foundation
SOS Malta
St. Jeanne Antide Foundation
Transplant Support Group