JOINT STATEMENT

Improving healthcare access for marginalised people

October 2019

NOBODY LEFT OUTSIDE

Improving healthcare access for marginalised people

Nobody Left Outside Thematic Network

Co-ordinating organisations

Organisations that have endorsed the NLO Joint Statement.

The Nobody Left Outside (NLO) initiative is supported financially by MSD

Introduction: addressing health inequalities in Europe

Across Europe, many underserved, marginalised people – including homeless people, lesbian, gay, bisexual, transgender and intersex (LGBTI) people, people who use drugs (PWUD), prisoners, sex workers, and people who are undocumented – are at high risk of poor health related to precarious living conditions and vulnerability.

These groups face substantial challenges in accessing health and support services owing to a variety of educational, cultural, organisational, administrative, economic and legal barriers, together with widespread stigma and institutional discrimination. In short, some of the people most in need of healthcare in Europe are among the least likely to receive it.

"Many of the populations that are most affected by HIV and related co-infections have poorer access to health and other services due to stigma, discrimination, criminalization, social exclusion and incarceration" EATG

> "... homeless populations, individuals with substance use disorders, sex workers, and imprisoned individuals experience extreme health inequities across a wide range of health conditions"
>
> **Aldridge et al. 2018**

Rationale to act

The case to address health inequalities and improve health and social care access is supported by a substantial evidence base and by various global and EU recommendations and policy frameworks.

In particular:

- The principle of health as a fundamental human right is enshrined in the International Covenant on Economic, Social and Cultural Rights (ICESCR) [United Nations 1976], while the European Pillar of Social Rights states that 'everyone has the right to timely access to affordable, preventive and curative health care of good quality'. These rights must be adequately established and protected in the new European legislature.
- The World Health Organization (WHO) has documented that significant health inequities exist across and within countries in the WHO European Region, linked to social determinants [WHO 2011; WHO 2014]. Accordingly, the WHO Health 2020 strategy aims to enhance health equity and improve health for all [WHO 2012].
- In 2019, G7 Health Ministers committed to improve healthcare access for all [G7 Health Ministers 2019].
- European Union (EU) Member States have committed to achieving the United Nations Sustainable Development Goals (SDGs) and Universal Health Coverage (UHC), whereby all people should have access, without discrimination and exposure to financial hardship, to nationally determined sets of basic health services. Health Commissioner Andriukaitis has specifically acknowledged the necessity to improve health and social care access for marginalised or vulnerable people, if these goals are to be met [Adriukaitis 2018].
- The wellbeing of people is also prerequisite for economic growth and social and economic stability in Europe. Finland's Presidency of the Council of the European Union in 2019 championed this approach in the context of the economy of well-being – showcasing the socio-economic benefits of disease prevention [EU2019.FI 2019].
- European Parliament Eurobarometer surveys have shown that almost two thirds of EU citizens would like to see more EU engagement in health and social security, with solidarity being recognised as critical to facing today's global challenges [European Parliament 2016].

> "It is only through a proactive and inclusive policy development and advocacy process that we can convince other parts of government and society that health is not a hopeless public expenditure, but is a resource for better economies, better quality of life and, ultimately, the way towards more just and more equitable societies. **— Zsuzsanna Jakab, WHO Regional Director for Europe**"

The Nobody Left Outside Initiative

The Nobody Left Outside (NLO) initiative is a collective of organisations representing some of the most underserved communities with respect to healthcare, including homeless people, PWUD, LGBTI people, prisoners, sex workers and undocumented migrants. United under the banner 'Nobody Left Outside', these organisations work together to identify shared challenges, share lessons learned through years of engagement, and seek integrated solutions to improve access to healthcare for the communities of people they represent.

Representatives of communities to whom a health service is targeted should be involved in service design, or redesign, to help ensure that it addresses relevant barriers to access [Onyango et al. 2017]. In response to this need, NLO participants co-created the NLO Service Design Checklist, which aims to promote a collaborative and evidence-based approach to service design and monitoring. It is intended to help service providers, monitoring and evaluation experts, policymakers and representatives of target communities (e.g. civil society organizations and patient groups) to design and deliver health and support services that are accessible to underserved, marginalised people.

Thematic Network joint statement: objectives and scope

As a Thematic Network, we have the opportunity to produce a Joint Statement. This Joint Statement has been co-created by NLO initiative participants with input from broader stakeholders via the EU Health Policy Platform.

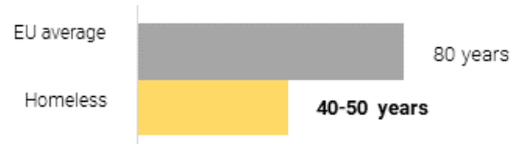
In health and social policy, the EU's main role is to support and complement the activities of Member States by encouraging cooperation and best practices. The EU can introduce policy frameworks that foster good health by supporting dynamic health systems that are integrated and people-centred, as called for by the G7 and Organisation for Economic Co-operation and Development (OECD), and address inequalities by engendering financially sustainable social protection and inclusion policies.

This Joint Statement aims to provide policymakers with a range of priorities, principles and recommendations on how to improve access to health and social care for Europe's most underserved people. It aims to translate the understanding of the determinants of poor health and unequal access, together with good practices and experiences of target communities, into concrete calls to action. Inequity is not inevitable.

Spotlight: health challenges of marginalised, underserved people

People in marginalised underserved groups are at a significantly higher risk of poor health than the general population, for example through infectious diseases (including HIV and viral hepatitis), mental health conditions, maternity health problems, poor dental health and violence-related trauma.

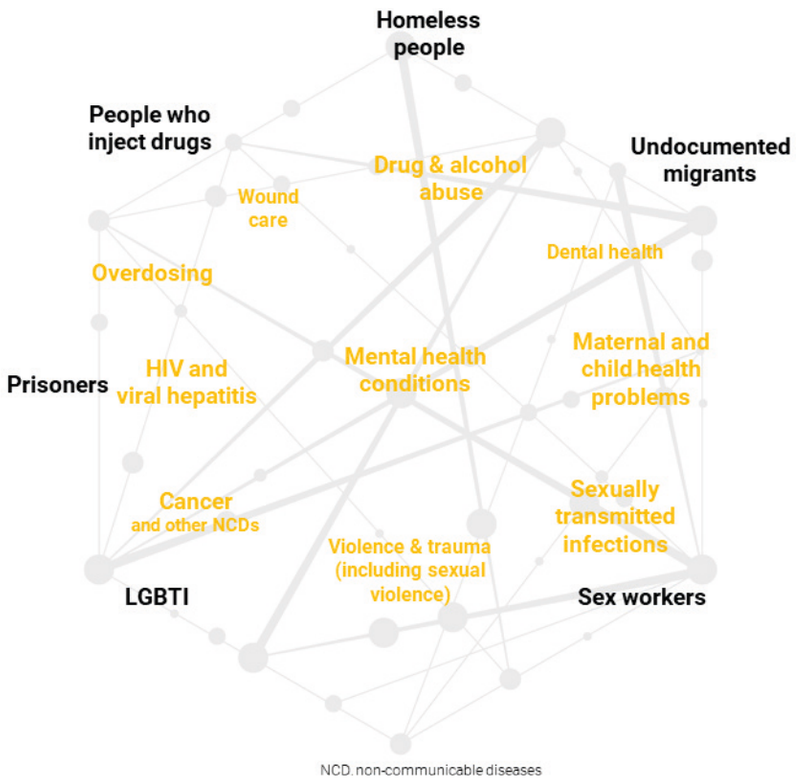
Homeless people live about half as long as the EU average



"PWUD over-represented in prisons – high risk drug and sexual behavior is common", EATG

*"Often there is an **overlap between drug use and sex work, homelessness, migration…"***
Correlation – European Harm Reduction Network

*"There is a 'slope' in health outcomes across socioeconomic groups in the general population and a '**cliff' when we consider homeless people"***
Lewer et al. 2019



Understanding the complex barriers to access

In addition to being at increased risk of poor health, marginalised communities face significant barriers to accessing healthcare services, owing to a complex interplay of educational, cultural, organisational, legal, administrative and economic barriers, together with widespread stigma and institutional discrimination. Key barriers highlighted by Thematic Network participants include:

Stigma and discrimination
- Among staff and at organisational level

Education
- Lack of staff education and training on needs of marginalised communities
- Lack of knowledge and information provision to user communities

Organisation
- Insufficient funding and coverage of low threshold services
- Lack of suitably accessible, community-based services
- Lack of integrated services providing 'continuum' of care

Legal and administrative
- Limited entitlements under national law, e.g. for undocumented people
- Negative effects of criminalisation, e.g. for PWUD
- Avoidance of healthcare services because of risk of deportation

"People who are undocumented face significant challenges in accessing services because of many factors. These include limited entitlements as well as fear, because they know that seeking help could lead to deportation". PICUM

*"In prisons, a **lack of effective harm reduction** measures, lack of peer educational programs and lack of training of prison staff strongly impact access" NPS Italia Onlus*

*"A major barrier to healthcare among sex workers is a **lack of information** about where to go for treatment or how to obtain health insurance." ICRSE*

Sex workers often face serious discrimination and other structural barriers in accessing health services. Those obstacles are often compounded by the intersection of sex work with other social vulnerabilities such as migration, LGBT identities, homelessness or drug use." ICRSE

Inequity is not inevitable – evidence of success

Inequity is not inevitable and there are numerous ways of addressing and overcoming these barriers. With even marginal investments a great change and impact can be established in offering solutions and improving access to health and social services to marginalised groups.

Successful innovative and practical solutions are being developed and used at national level. These include:

Community-based services User-friendly disease testing, treatment, prevention, counselling and health information, e.g. 56 Dean Street clinic and Checkpoint Centres (e.g. Athens, Barcelona)

Integrated care services with different specialities and expertise co-located or linked

Harm reduction programmes among PWUD, in prison and community settings– shown to be cost-effective

Digital tools that foster integrated care, e.g. CONNECARE and the Advanced Symptom Management System

Stable housing programmes – housing has an extremely important yet widely neglected impact on healthcare access and outcomes

Local authority initiatives to foster commitment, e.g. Fast-Track Cities

Call to action statement

We, the undersigned organisations, call upon the new European Commission and European Parliament, and EU Member States, to increase EU leadership addressing cross-border health challenges and specifically to recognise the crucial importance of:

- Addressing social determinants of poor health
- Delivering equitable access to healthcare and support services (e.g. housing and legal services) to all people in Europe, including marginalised and underserved groups at risk of severe vulnerability
- Providing integrated care services in order to ensure a 'continuum' of care to marginalised and underserved communities
- Maximising the opportunities of digital transformation of health and care to increase affordability and availability to the best quality diagnostic tools and treatments for marginalised communities
- Researching and addressing the specific health challenges faced by marginalised, underserved communities, together with the barriers these groups face in accessing healthcare and support services.

We call on the European Commission, European Parliament and EU Member States to take heed of the following six actions to ensure that nobody is left outside our health systems.

NLO commitment

Community engagement is fundamental to addressing the complex problems faced by underserved people. The NLO participants and Thematic Network partners stand ready to support the EU and its Member States to improve the situation of those left outside in Europe.

NLO participants are committed to the calls to action in this Joint Statement and commit to provide and discuss evidence-informed documentation (including recommendations and the exchange of best practices) with decision-makers and to help narrow the gap between policies and operational interventions.

NLO participants commit to provide technical support and to leverage our networks to collaborate with all EU institutions and agencies, and other stakeholders, to implement the calls concerning a knowledge platform and a joint action.

NLO particpants commit to provide expert assistance to support training of healthcare staff and other workers to help address stigma and discrimination.

NLO participants are ready to prepare and submit a proposal for a Pilot project on the use of the NLO Service Design Checklist in practice.

NLO participants to commit to ensure that 'health is social policies' and the community-based approach feature on the EU policy agenda.

Call 1. Knowledge platform

The European Commission should support the establishment of an EU-level knowledge platform to compile and share research and best practices in healthcare access for marginalised, underserved groups.

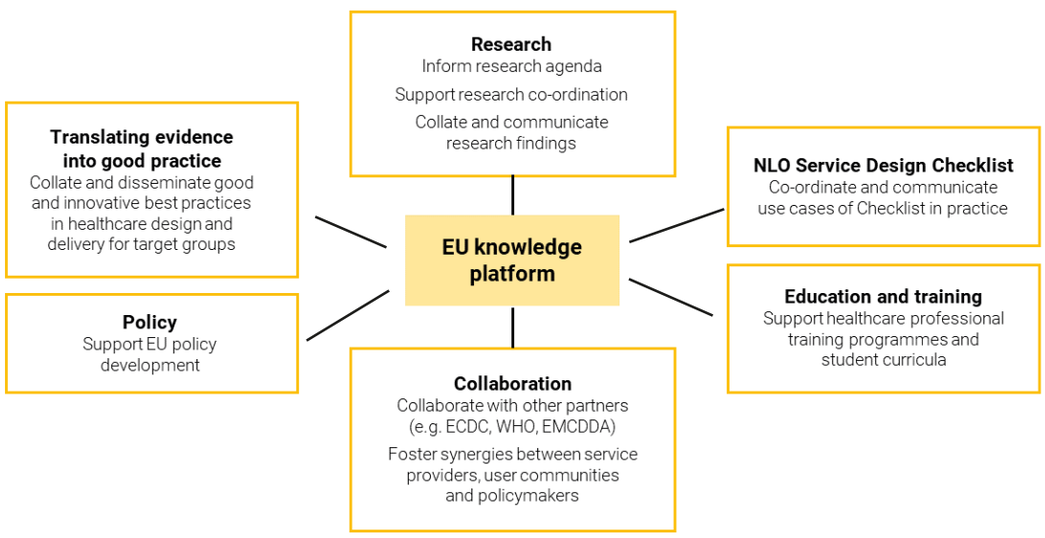
Context and rationale

Marginalised, underserved groups have specific and complex healthcare needs warranting specialist expertise. At present, specific expertise, research and interventions are limited and scattered across Europe.

This situation is comparable in some respects to that of rare diseases, which are being tackled in part via the European Reference Networks (ERN) programme, implemented under the Cross Border Directive. Accepting that many healthcare systems across Europe are failing people who are homeless, the EU Expert Panel on effective ways in investing in health has advised that ERNs are not the best solution to this community and other vulnerable groups [Expert Panel 2018]. However, the Panel urged Member States and the EU to optimise the care for these groups through the creation of platforms and 'Learning Communitie' in Europe with participation of multiple Member States and experts in the different domains.

Recommendations

- We call on the EC to support, within the next EU health programme, an **EU-level knowledge platform** to compile and share research, evidence, expertise and experience in healthcare access for marginalised, underserved communities.
- This should be led by academics active in this field, in close collaboration with civil society networks and organisations, in particular those representing underserved communities and groups such as the NLO community. Its functions could be represented in this figure:



Call 2. Health workforce education and training

The European Commission should support healthcare training and capacity building via the European Social Fund+.

Context and rationale

Health and social care providers often lack suitable education and training to deal with the complex challenges faced by marginalised communities. Negative attitudes among health professionals towards marginalised groups can also contribute to stigma and discrimination and be an important barrier to access.

All staff members who serve such communities therefore require specific education and training to enable them to deliver the service. For example, medical education curricula should include training to support staff in:

- Working with diverse communities and patients with complex needs (including cultural sensitivity). Good examples include the migrant-friendly hospital programme in Switzerland [Hudelson et al. 2014]
- Applying integrated care models that connect health and social services across disciplines to provide holistic care, such as that developed in Ghent, Belgium [Van Landshoot et al. 2018]. The WHO has proposed health workforce competencies suitable to realize coordinated/integrated health services delivery [Langins & Borgemans 2015].

In the next EU budget for 2021–27, the Commission proposes a new European Social Fund Plus (ESF+). A key focus of the ESF+ is to promote social inclusion and health, e.g. by enhancing timely and equal access to affordable, sustainable and high quality services. This includes supporting integrated work to implement best practices for the promotion of health, prevention and management of diseases, and for innovation in public health [EC 2018].

Recommendations

- The European Commission should support healthcare training and capacity building via the European Social Fund+ (ESF+).
- Programmes should include:
- Suitable training to educate and enable all staff providing services for marginalised communities, including healthcare professionals in hospitals and clinics and staff working in social care and community settings (e.g. in social care, hostels and prisons)
- The European Commission should also support peer training and other means of empowerment of service users, including early disease detection and health literacy, e.g. through mobile-based monitoring systems.
- In addition to healthcare education, education should 1) include training to avoid stigma and discrimination, 2) aim to reinforce collaboration between healthcare staff and community workers to facilitate linkage to a care continuum.

Call 3: Pilot project: NLO Service Design Checklist implementation

The European Commission should support a Pilot Programme to evaluate the implementation of the NLO Service Design Checklist.

Context and rationale

The NLO Service Design Checklist has been developed to help health service providers, monitoring and evaluation experts, policymakers and representatives of target communities (e.g. civil society organizations and patient groups) to design and deliver health and support services that are accessible to underserved, marginalised people. It is freely available at www.nobodyleftoutside.eu.

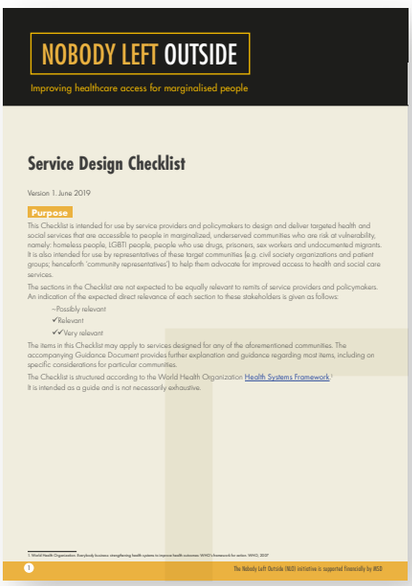
The NLO Checklist promotes the implementation of integrated (co-located or linked), community-based, people-centred and needs-based health services, together with housing, legal and social support services, in alignment with the goals of UHC.

It is structured into six sections according to the WHO Health Systems Framework, namely: 1) service delivery, comprising design state, services provided, accessibility and adaptation, and peer support; 2) health workforce; 3) health information systems; 4) medical products and technologies; 5) financing; and 6) leadership and governance. The NLO Checklist should be piloted in practice before wider implementation.

The European Commission supports experimental Pilot Projects to test the feasibility of actions and their usefulness. Previous pilot projects include Health4LGBTI), which aimed to help reduce health inequalities experienced by LGBTI people.

Recommendation

- The European Commission should support a Pilot Programme to co-ordinate and evaluate selected implementations of the NLO Service Design Checklist.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Improving healthcare access for marginalised people

Service Design Checklist

Version 1. June 2019

Purpose

This Checklist is intended for use by service providers and policymakers to design and deliver targeted health and social services that are accessible to people in marginalized, underserved communities who are risk at vulnerability, namely: homeless people, LGBTI people, people who use drugs, prisoners, sex workers and undocumented migrants. It is also intended for use by representatives of these target communities (e.g. civil society organizations and patient groups; henceforth 'community representatives') to help them advocate for improved access to health and social care services.

The sections in the Checklist are not expected to be equally relevant to remits of service providers and policymakers. An indication of the expected direct relevance of each section to these stakeholders is given as follows:

–Possibly relevant

✓Relevant

✓✓Very relevant

The items in this Checklist may apply to services designed for any of the aforementioned communities. The accompanying Guidance Document provides further explanation and guidance regarding most items, including on specific considerations for particular communities.

The Checklist is structured according to the World Health Organization Health Systems Framework.[1]

It is intended as a guide and is not necessarily exhaustive.

[1] World Health Organization. Everybody business: strengthening health systems to improve health outcomes: WHO's framework for action. WHO; 2007

1

The Nobody Left Outside (NLO) initiative is supported financially by IRSD

Call 4: Joint Action

The European Commission should support a Joint Action to improve access to health and support services among marginalised and underserved communities, which should include the implementation of guidelines for monitoring and evaluation.

Context and rationale

International collaboration between academia, advocacy organisations and healthcare providers is necessary to drive improvements in healthcare access for underserved communities, for example as called for by the Expert Panel on Effective Ways Investing in Health [Expert Panel 2018].

EU Joint Actions are collaborative actions to develop, share, refine, test tools, methods and approaches and to build capacity. Joint Actions are co-financed by European Commission and Member States.

Recommendations

- The European Commission should support a Joint Action to improve access to health and support services among marginalised and underserved communities. Such a Joint Action could include priority issues such as multimorbidity and polypharmacy, as well as access to new digital technology, noting the widespread use of smartphones in Europe.
- Several Joint Actions (e.g. HA-REACT, INTEGRATE, Joint Action Health Equity Europe), as well as pilot projects (e.g. Health4LGBTI), have made important progress, relevant to this Thematic Network, in selected communities. This progress has often been focused on infectious disease. Now, however, attention should also be provided to marginalised communities and non-communicable diseases.
- A Joint Action could build on these actions (thereby helping to extend their value), while also developing and evaluating new approaches to improving healthcare access common to marginalised underserved groups (e.g. using and refining the NLO Service Design Checklist, which entails community engagement in health services development and re-engineering).
- The NLO Service Design Checklist could be integrated in existing Joint Actions and other European Commission funded projects to maximise their scope for action (i.e. INTEGRATE) and/or suggest new approaches to improving healthcare access common to marginalised underserved groups.
- The European Commission should encourage the OECD to maximise the outreach of the main outcomes and data linked with the implementation of checkpoints and care programmes, via the Health at a Glance: Europe report [OECD 2018].

Call 5. Horizon Europe: cancer in underserved communities

The Horizon Europe research programme mission on cancer should support funding for research to help improve access to cancer screening and care services among people in marginalised underserved communities.

Context and rationale

Some cancers are more common in marginalised group (e.g. liver cancer in the homeless), as compared with the general population, or have worse outcomes owing to delays in diagnosis and access to care. Cancer diagnosis and care is challenging among these communities. There is considerable variation in practice and optimal care models are not well established.

Improving cancer care and outcomes is a key health priority of the new Commission. Cancer is one of five missions of the Horizon Europe research and innovation programme. Accordingly, this should include attention to communities in whom disparities are most acute.

Recommendation

- The Horizon Europe research programme mission on cancer should support funding for research to help improve access to cancer screening and care services among people in marginalised underserved communities.

Call 6: Health in all policies

The European Commission should further prioritise a co-ordinated approach to addressing social determinants of health in all policies.

Context and rationale

Healthcare should not be taken in isolation, but it is inextricably interconnected with lifestyle, living conditions and other socio-economic determinants.

This is particularly apparent within the communities who are the focus of this Thematic Network, who are at high risk of extreme vulnerability and precarious living conditions.

We welcome the emphasis by the Finnish Presidency of the Council of the EU on the economy of well-being [EY2019.FI 2018]. We agree with the approach that wellbeing and economic policy go hand in hand, with the aim to ensure inclusion and equal opportunities for all, and that efficient preventive health services pay for themselves many times over.

Recommendation

- The European Commission should ensure strong coordination and put in place joint activities (i.e. calls for proposals) between its various DGs (e.g. DG CONNET, DG SANTE, DG EMPL). This should aim to put into practice a coordinated approach that may address social determinants of health in all policies and consider the health impacts of policies beyond the health sector, such as the Digital Single Market.

> The extreme burden of disease experienced by these populations demands a cross-sectoral response. — **Aldridge et al. 2019**

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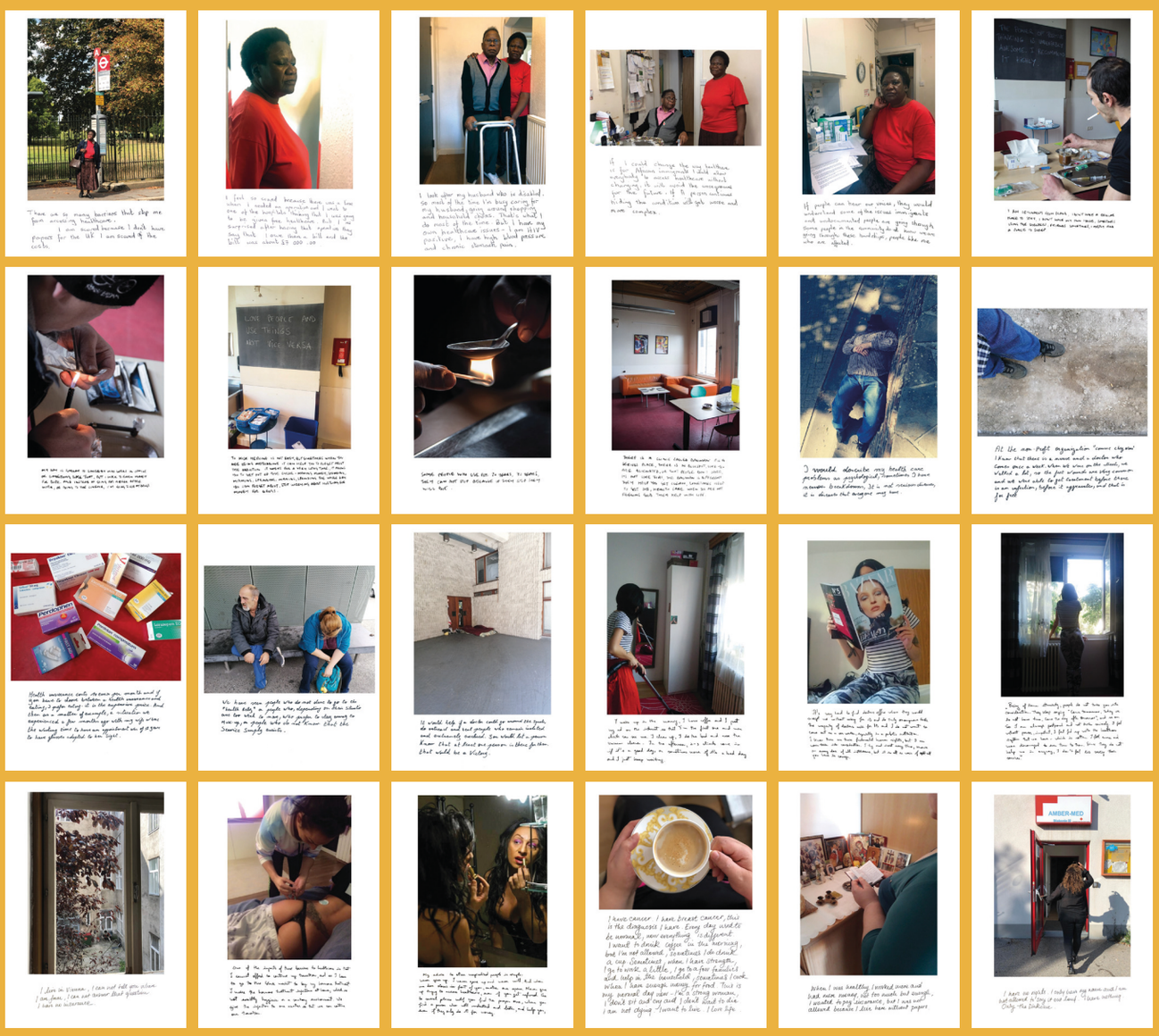

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