Distr.
GENERAL

CES/AC.36/1998/15
EUR/ICP/INFO 020603/15

6 August 1998

Original: ENGLISH

STATISTICAL COMMISSION and
ECONOMIC COMMISSION FOR EUROPE

WORLD HEALTH ORGANIZATION
REGIONAL OFFICE FOR EUROPE

CONFERENCE OF EUROPEAN STATISTICIANS

Joint ECE-WHO Meeting on Health Statistics
(Rome, Italy, 14-16 October 1998)

SESSION II : The role of IT in collecting health information

HEALTH STATISTICS IN FINLAND -DISSEMINATION WITH INFORMATION TECHNOLOGY

Invited paper submitted by the National Research and Development Centre for Welfare and Health, Helsinki, Finland [1]

1. INTRODUCTION

1.1. Facts about Finland

Finland is situated in Northern Europe. It has a population of 5.1.million, with 16.8 inhabitants per square kilometre. These people are living in 453 municipalities (population range 150 to 500 000). Finland has an 80 years-old history of independence and western democracy. It has been a member of the European Union since 1995. Finland is a highly industrialised country with a high level of education. Finnish companies are market leaders in some high-tech branches (e.g. Nokia in communication technology) and Finland has the highest density of internet usage in the world. The Finns are specialised in winter sports. Although Finland has not yet qualified for the football world championship finals, a Finn has won the Formula One race several times (e.g. Mika Häkkinen 1998).

[1] Prepared by Mikko Nenonen, Dr. Med., Development Manager & Olli Nylander, Head of Unit for Statistics and Registers

1.2. Social Welfare and Health Care Services in Finland

Finnish social and health policy has always stressed the equal availability of services. The intention has been to provide services to all regardless of social group, income or place of residence. Finland uses, for example, less than 8 % of its GDP on health care (OECD 1997) with 75 % of money coming from public sources. The goals of the Finnish social and health policy in the future are to ensure that all population groups have even better access to social and health care services which are effective and of high quality; to stress the priority of open care services; to support smooth co-operation between primary care and specialised care and also between social and health care services; and to give municipalities increased influence over the provision of services (Ministry of Social Affairs and Health 1997).

Municipalities bear the main responsibility for the provision of social welfare and health services. Most provide their social welfare services independently while their health services are provided through their own multi-professional health centres and health centre hospitals - the smallest municipalities form joint municipal authorities for this purpose. For the provision of specialised care, the country is divided into 21 hospital districts with several hospitals in each district, although in this respect Helsinki University Hospital constitutes a hospital district of its own. A major part of the primary health care services for people of working age are provided by the occupational health services. Finland has also well-organised private health care services for both primary and specialised health care. These are partly financed by the Social Insurance Institution. Roughly 42 % of all health care expenditure was spent on in-patient services and 35 % on out-patient care. Finns have yearly about 1.3 hospital days per person in specialised care and 1.5 in primary care. Each Finn has a mean annual average of 1.1 specialist consultations and 4.5 primary care consultations in public sector and 0.6 in private sector (Ministry of Social Affairs and Health 1997).

1.3. Social Welfare and Health Care Statistics in Finland

The responsibility for national social welfare and health care statistics has been divided in Finland between Statistics Finland and National Research and Development Centre for Welfare and Health (Stakes) both of which are official statistical authorities in this field. Statistics Finland collects and publishes the economic and manpower statistics. Stakes' field of activity is the service structure of Social Welfare and Health Care: birth statistics, day care statistics, hospital statistics, income support and child allowances, etc. Most of this information comes from nation-wide client-patient registers based on individual personal identification numbers (PIN). This makes it possible to link different in-patient episodes and even different registers together.

In Finland the borderline between social welfare and health care services is becoming more and more theoretic. In practice both these sectors work in

close co-operation. There is, however, high variation between municipalities. Some forms of services (e.g. long term institutional care for dementia patients) may be produced in some municipalities by health care system and in others by social welfare system). This is why in the Nordic and especially in the Finnish model both sectors have their own high quality statistics on individual level. Having registers from both sectors makes it possible e.g. to calculate the total need of resources in the treatment of dementia.

The Finnish social welfare and health care systems have mainly public financing. This is why the main content of the statistics is the use of the social welfare and health care system as a whole , not the use of resources (money) or production of operations and other "products", like in the insurance financed systems. The latter system gives you naturally a more detailed picture about the health care expenses and fees than the Finnish system.

1.4. International statistical co-operation

Finland is active in many international organisations, including statistical co-operation. Statistical co-operation between the Nordic countries (Denmark, Finland, Island, Norway and Sweden) has long traditions. We present here this work in more detail, because it may not be so well known outside the Nordic countries. The Nordic Medico-Statistical Committee (**NOMESCO**) was set up in 1966, following a recommendation by the Nordic Council. In 1979, the Committee was made a permanent statistical committee under the Nordic Council of Ministers with separate fundings from the Nordic Committee on Social Policy. Today, the Committee has a permanent secretariat in Copenhagen. The aim of NOMESCO is as follows:

- To be responsible for the co-ordination of the health statistics in the Nordic countries.
- To initiate new projects, partly to improve comparisons of statistics, and partly to ensure the most rational use of Nordic expert knowledge in the field.
- To inform about Nordic statistical activities, mainly by publishing annual statistics as well as the results of special projects, surveys, etc.
- To co-ordinate and take part in international statistical collaboration, including activities in the Baltic countries and the Russian part of the Barents Region.

The Nordic Social-Statistical Committee (**NOSOSCO**) was set up in 1945. The aim of NOSOSCO is as follows:

- To be responsible for the co-ordination of the social statistics in the Nordic countries and to undertake comparative analyses and descriptions of the scope and the substance of social security measures.
- To initiate new projects to improve comparisons of statistics.
- To inform about Nordic activities, mainly by publishing annual statistics as well as the results of special projects, surveys, etc.
- To co-ordinate and take part in international statistical collaboration, including activities in the Baltic countries.

The responsibility about the NOMESKO and NOSOSCO co-operation is divided between Ministry of Social Affairs and Health, National Research and Development Centre for Welfare and Health (Stakes), Statistics Finland and National Public Health Institute. Both NOMESKO and NOSOSCO publish yearly a high quality statistical yearbook of their field of activity. For more information see http://www.nom-nos.dk/nososco.htm .

International health statistics are also collected and published by WHO, OECD and EU / Eurostat. The national responsibility of this co-operation has been divided in Finland between Stakes and Statistics Finland. Stakes bears the main responsibility for WHO and OECD co-operation in this field and Statistics Finland for EU / Eurostat. The diversity of international co-operation sets high demands for national co-operation if one wishes to avoid double, triple and even quadruple work in collecting and delivering statistical data abroad. In Finland we have organised a national working group on international statistics with members from all organisations involved. This working group has greatly increased our understanding of the international statistical systems, and also created pressure to avoid overlapping work in the international organisations.

1.5. National Research and Development Centre for Welfare and Health (Stakes)

The National Research and Development Centre for Welfare and Health, Stakes is an independent, non-political institution, financed by Ministry of Social Affairs and Health. Stakes is a public professional centre and its customers are public and private decision-makers, professionals, specialists, administrators, service producers, research communities, researchers, students, media and citizens in Finland and abroad. Stakes has three highly integrated tasks:

- Research
- Development
- Information bank (social welfare and health care statistics)

This structure creates synergy between statisticians and experts in the field of social welfare and health care research. Stakes is not an administrative organisation. It has no control or supervisory roles. The previous strict norms have given place to steering with information.

There has been a lot of organisational development in the field of social welfare and health care organisations in the last few years. Social welfare and health care services have been integrated. New services have been created between open and institutional services. The local authorities need models of good practices not authoritarian norms and rules as previously. Local authorities must know what is the most effective and economic way of organising services. Stakes provides this information to help local authorities in decision making. This means that municipalities can compare their own functions with other municipalities. In this task Stakes combines the information derived from the high quality register-based statistics with the expertise of scientific researchers and experienced social welfare and health care administrators.

2. INFORMATION FLOW FROM THE CARE INSTITUTIONS TO THE STATISTICAL OFFICE

2.1. Data from the care institutions

Data are created in the everyday work with clients in the social welfare and health care organisations. The amount of data are largest at this level. Also the data are far from structured, use only few codes etc. The data are used in the care work and are connectable to individuals by unique personal identifier numbers (PIN). They are also used for administrative and statistical purposes at the local level. Most of the data are in form of computer databases.

The Finnish legislation gives Stakes right to get from the care institutions all the information which is needed for statistical and administrative purposes. This information must be collected, processed and published according to strict data security rules and with high statistical ethics. This right has been accepted and there are no major refusals of data delivery. This means that the Finnish social welfare and health care registers cover practically all the activities in their field (excluding naturally the minor and random dropouts).

Stakes collects both aggregated data, and individual data (with PIN codes). The data about the out-patient services are mainly collected in aggregated form. This means they can not directly be linked with the in-patient data. The yearly amount of e.g. out-patient visits to the primary care doctors is less than 30 million. In a small country like Finland this would not be too large data set for even register based data collection. Data from in-patient services are collected as individual data.

The traditional way to transfer data from care institutions to statistical office is by post and by printed forms. The more advanced way (used mainly in Finland) is to use diskette and send it by post. The development of technology makes it possible to change the information flow as much as possible from physical media (paper or diskette) to flow of bytes. In the future data will be transferred via communication networks. This demands high level of standardisation and harmonisation of the data and the data collection. This, however, makes it possible to pick out just the information needed and in such form that is ready to be used in either statistical, administrative or scientific work.

2.2. Individual data collection process

Stakes collects data from the social welfare and health care institutions. Providers of health care services include 21 (+2) hospital districts, 250 primary health care institutions and 50 private care institutions. In the social services, service producers total about 1800. It includes old people services, services directed at alcohol and drug problems, services to disabled people etc. There is also a large private sector that especially produces so-

called half-open services, - largely various kinds of service homes.

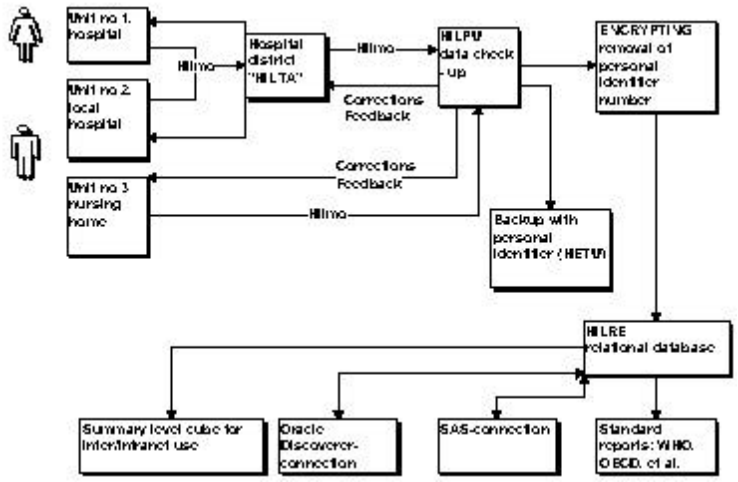

Figure 1. The data collection and refining process. Discharge reports (Hilmo) are sent yearly to Stakes from care institutions. Before sending they are scrutinised for technical errors at the institution (HILTA-program). At Stakes the data are analysed, checked and corrected both manually and with a computer program (HILPU). At this stage the provider of the data receives an automatically produced, customised report based on this information. Personal identifier is then encrypted and the data are included into the relational database (HILRE). This is used for reporting and research purposes.

The collection process has many phases and its path depends on the capabilities of the data providers. At one end of the process everything is done by filling in paper forms while at the other end of the process everything is done by information technology. The data collection technology may be integrated into commercial information systems (30 different systems and 5-10 market leaders). Stakes is in close contact with the producers of these systems, and there is a standardised transfer file format for data collection. For smaller organisations Stakes distributes a free product, so-called HILMO-PC (based on the Paradox/Access-program) for collecting data. About 700 producers are using this product. This product includes classifications, definitions, rules, etc. and it includes also a reporting systems. HILMO-PC has a very high standard of data protection technology and has been tested by the Finnish Data Ombudsman’s Office. The new version of HILMO-PC program will be multilingual and run in Windows/NT operation systems. The process of data collection is presented in the Figure 1. Stakes collects individual data of some special health conditions, too: births, congenital anomalies, abortions, sterilisations, cancer, sight disabilities. In the social welfare Stakes has a special collection process for income support and child welfare.

Because Stakes is collecting individual patient data (also with PIN codes) the level of data security must be high. The Finnish legislation gives Stakes right to handle this kind of material. The use of PIN codes is also widely

accepted. Individual data with PIN codes is given out from Stakes only for scientific purposes and only when you need these codes in linking different databases together. This data are not used in contacting patients or making administrative or treatment decisions concerning individuals. There have not been any data security violations during the decades of Finnish health registers.

2.3. Aggregated data collection process

Stakes receives aggregated (other than register based) data from many sources. Statistics Finland is e.g. responsible for municipal data collection including data on economic conditions labour force etc. The data about out-patient services are also collected in aggregated form. There is, however, increasing demand to switch to register based data collection also in this field. Stakes is responsible for data collection in the private social welfare and health care sectors.

2.4. Bringing together different individual databases

Treating social and health problems needs many institutions and professionals. Register based data collecting makes it possible to link together several databases with information about the same individuals. For example, people who use home assistance services often use home health services and many institutional services as well. Register linkage is, however, used only for statistical or in special cases, scientific purposes. These data are not analysed on personal level or used in the treatment or in decision making concerning registered individuals. Stakes avoids using the real personal identifier codes in its work , instead an encrypted identifier or plain case number is used.

3. FEEDBACK AND REPORTING SYSTEM

Feedback and reporting system working as much as possible in real-time, or at least some reporting system is the basis of high quality statistical system. Data that is not reported publicly "gets spoiled" in very short time. This means, that the lack of feedback makes data collection to an extra burden for the data providers and they do not see the importance of the quality of the data. If the data providers see their data published and used in e.g. decision making and comparisons they are ready to improve their data quality. In this way national and regional statistics may become useful tools even for the local use.

Feedback starts with an automatic and immediate feedback report (on paper) to the service producers and information senders. This report is produced when their data are first time checked at Stakes. When the data have been carefully checked for systematic and logical errors and corrected they are included into the relational database. From this database about 20 - 30 yearly statistical reports (with an English summary) are produced. The first basic reports are produced within six months after the end of the statistical

year (e.g. total first reports on the 1997 material were published in June 1998).

The new information technology has made it possible to create intelligent and safe database access systems, too: ***Net-Hilmo and Theme-Net*** directed primarily to producers and municipalities, but also to ordinary citizens, ***Sotka***, a statistical database or "library", directed mainly to the municipalities. There are also customised reporting systems ("Statistical report for the municipalities") and systems similar to research reporting; for example, about differences of service structures, and seamless care i.e. service chains/pathways.

3.1. Net-Hilmo, Theme-Net (HTTP://info.stakes.fi/nettihilmo)

The data in the national Stakes registers are systematically organised, carefully checked, and use standard classifications. This makes it possible to disseminate the data with the latest technology with minimum effort and expense. The modern technology makes it also possible to open to public use data, which is based on personal level information but with no access to personal data. The basic database solution is Oracle 7.x, run on a HP9000 computer. Stakes uses Oracle Discoverer and SAS programs to access the patient level data for statistical and research purposes. For public use a summary level database without patient level data are created with Cognos Impromptu - program. This database is then transformed into a Cognos PowerPlay database or more precisely: multidimensional data cube to be placed in Stakes Internet server.

The new web page "The Net- Hilmo" can be accessed by health care and social welfare professionals, researchers, decision-makers, citizens and media in Finland and abroad. The Net- Hilmo is designed to be compatible with any Internet web browser. No additional software is needed. The Net- Hilmo provides statistical data on various patient groups in the whole country, in a hospital district, region or province. Special procedures have been undertaken to secure data protection. All data and instructions are given in Finnish, Swedish and English. Definitions of employed variables are provided. The main elements of the Net- Hilmo are depicted in the Figure 2 below.

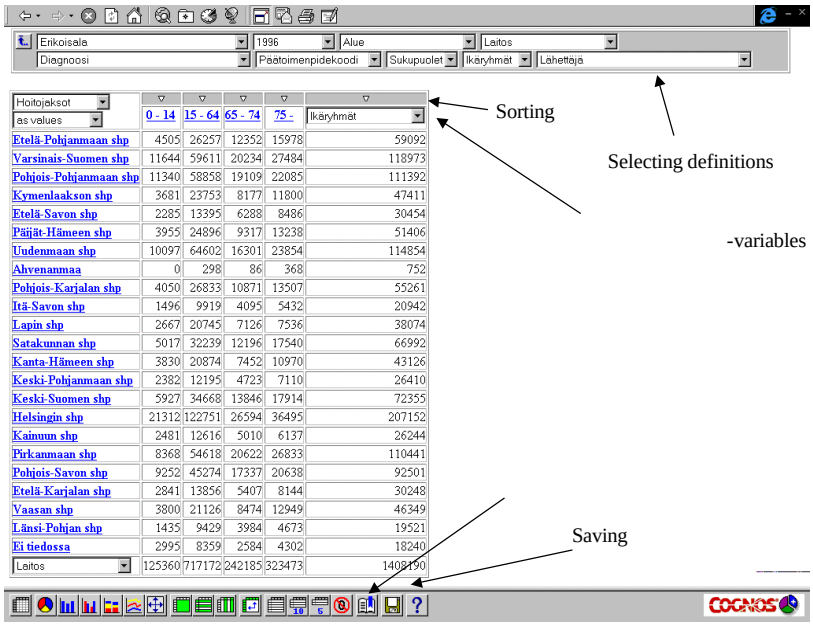

Figure 2. Net- Hilmo interface

The Net-Hilmo gives you an overview of the Finnish health care. The parameters used are: year, medical speciality, region of the patient, hospital district, diagnosis (main groups), operations (main groups), age groups, sex, organisation referring the patient to institutional care. The used numeric variables are: number of treatment periods, number of patient days, waiting time and the price of the treatment. The interface is able to produce over one billion different printouts, and reacts to user commands within a few seconds. Stakes also produces for hospital districts and municipalities a more detailed, password protected (for which a fee is charged) interface which gives access to institution or municipality level of data and to a deeper level in diagnoses and operations. Theme-Net is a cube where groups of service users are in a central role. Different groups are elderly people, alcohol abusers, mentally handicapped, etc.

3.2. Sotka-database

Sotka is a statistical data base. OVT/EDI-transfer system is the route from the data base to the providers' computer. The data base is run on a HP-9000-computer. The data base includes 3000 raw indicators and 200 ready-made indicators. The smallest area is one municipality . Sotka-data base is a collection of data from several databases (care registers, aggregated population, functional, resource and cost information of Statistic Finland) designed from the viewpoint of municipalities. Sotka has about 250 municipality and 250 other users. The main users are Stakes and Ministry of Social Affairs and Health. During the last year Sotka-licence has been offered to every Finnish municipality free of charge. In the future Sotka will also go into Internet.

3.3. Automatically produced statistical report for the municipalities

Stakes has developed a client oriented customised report that is aimed at professionals, politicians, developers and researchers in the municipalities. In this product benchmarking and peer review methods are used to provide tools for analysis of differences in services structure. Statistics include information about population, indicators of the need for services, cost information and information on the use of services. One example of the 40 printouts included in this report is presented in Figure 3.

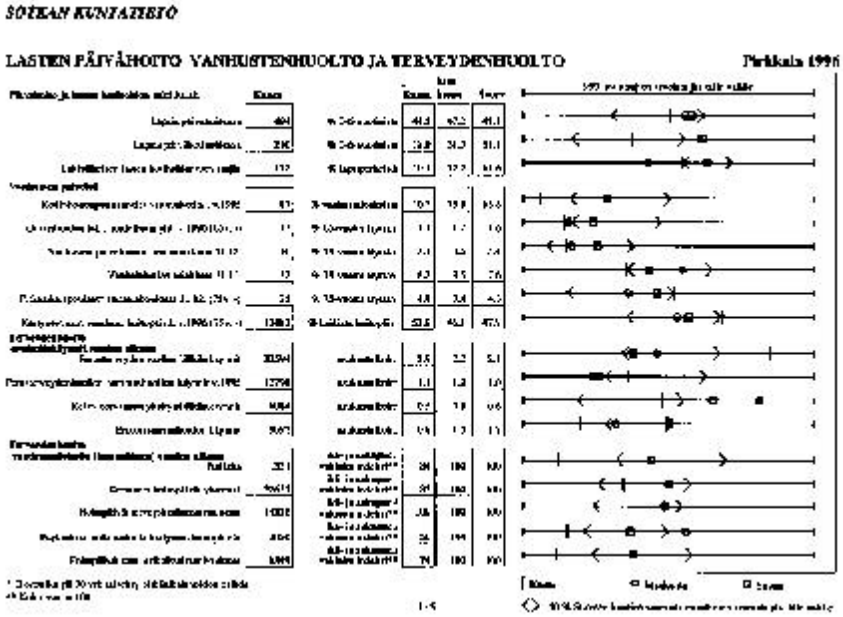

Figure 3. The child day care, care of old people and health care benchmarking (the lines on right) for a Finnish municipality depicting its performance (|) compared with other Finnish municipalities, its neighbours and 95% and 50% intervals.

3.4. Other examples of the use of Stakes registers and statistics

3.4.1. Service structure analyses

The freedom of 453 municipalities in Finland to organise their health and social services has caused considerable variation in local services. National social and health registers make it possible to analyse these services in detail. In one study we used sex and age adjusted indices (year 1995) for: somatic and psychiatric hospital care, use of health centre hospitals, use of old people's homes, service housing, home health care and assistance, institutions for the mentally handicapped and non-adjusted numbers of visits to private physicians for each of the 455 municipalities. The majority of municipalities are grouped near the national average. There were remarkable clusters with significantly different settings (p=0.0001 in all components, MANOVA). A group of 75 municipalities, for example, had greater use of service housing and lesser use of health centres. The expenses of the social and health services (minus expenses of child day-care and living allowance)

varied significantly between the ten sub-clusters (p=0.0006). The main components associated with variation in net-expenses, were somatic hospitals and health care centres. The effects of service housing and home care on expenses were statistically insignificant. Grouping of municipalities into groups helps them to make comparisons with units with similar sets of service provided.

3.4.2. Service chains - seamless care

It is necessary for the patient/client to have some continuity of care. It is, however, very common that subsequent care institutions do not know enough about the patients' situation. The Finnish data security law is so strict that the information can not be used in the next place without the client's permission. In our project we first identify the most common service lines. We are also developing a new information system to help the decision-makers. Some results of our research are as follows:

- Most short and "simple" service chains contain surgical or other operations, and the service process is limited to one institution (e.g. open-care contacts and institutional care in one hospital)
- Conservative treatment like internal medicine and psychiatry show more variation. There are two main lines: Simple, where the problem of the patient is well defined, and we know the result of the care; Complex, where patient has many problems, and the result of care is unclear
- Chronic problems form one chain of their own
- Mentally handicapped people form their own closed care field where people use own care structure.

Register based data make it also possible to analyse the shared customers within social welfare and health care services. For example over 70% of people in home services use institutional services (nursing home services, institutional health care services).

4. THE STATISTICAL SYSTEM OF THE FUTURE

As a statistical authority Stakes has two major challenges. One is to minimise data collection (especially individual data). The other is to increase the quality of data and to produce more and more detailed statistics. There is a conflict between the fear of exaggerated data security and of high collection costs on the one hand, and the needs of government, municipalities, researchers, politicians, etc, on the other. There is a clear need for more detailed information on open care, intermediate care, institutional care and service network as a whole. The strategy of Stakes is to automate and standardise the collection process with the new information technology, and to extend data collection by voluntary agreement. Relational data base architecture is the basis of the data collection and reporting.

Reporting is switching from printed reports to Internet. The published statistics will have a direct connection to administrative, quality etc. needs. Most of the current printed reports are published as interactive Web-pages, where you have possibility to go into details after you have viewed the figures on national level. Also the data delivery for the international

statistics is possible to implement with a Web-page. In the future Stakes will have an integrated system on the Internet, where Net- Hilmo, Theme-Net and Sotka are available for every one who has licensed a password into the system. This will form an information centre for citizens, professionals, politicians and researchers in Finland and abroad.

REFERENCES

Ministry on Social Affairs and Health (1997). Guidelines on Health Care in Finland. Publications 1997:14, Helsinki, Ministry on Social Affairs and Health

OECD (1997). *Ecowin97 Database*

Internet addresses:

http://www.stakes.fi/english/index.html Stakes homepage in English
http://www.stakes.fi/tilre/tilfacts.htm The homepage of Statistics an d Registers Unit at Stakes
and "Facts about Finland" reports
http://info.stakes.fi/topi / The Finnish codes of care institutions
http://info.stakes.fi/nettihilmo/ The Net- Hilmo and Theme- Hilmo homepage