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## Surveys and services

*The feasibility of conducting research in Swedish  
community pharmacies*

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### **Abstract**

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For the past decades, there has been a shift in community pharmacy practice from dispensing and compounding towards provision of pharmacy services. Research is important to generate evidence for new services within pharmacy practice. Pharmacy practice research can be divided in two main themes: research related to pharmacy as a data source and to the pharmacy as the object of research, respectively.

The purpose of this thesis is to increase the understanding of the conditions required for successful involvement of Swedish community pharmacy staff in pharmacy-based research, and to evaluate the data generated through a certain type of research: pharmacy-based patient surveys on drug utilization.

Specific aims were to evaluate if there is a selection bias in drug utilization surveys conducted in Swedish community pharmacies, to explore the experiences of pharmacists either conducting the surveys or recruiting patients to research on adherence-promoting services, and to describe barriers and facilitators to conducting research in community pharmacies.

Data were collected via pharmacy-based patient surveys, dispensing data, individual interviews, a cross-sectional staff survey and focus group interviews.

In community pharmacy-based surveys or services research, with the dispensed drug as the trigger for inclusion, patients aged 75 years or older are underrepresented since they less often visit the pharmacy to redeem their prescriptions themselves. Due to their perceived workload, dispensing pharmacists sometimes avoid including patients perceived as complex due to age, polypharmacy or communication difficulties. These processes contribute to a healthy selection effect in both types of research and pharmacy services not reaching the patients in most need of support with their medication.

The pharmacists were generally positive to conducting surveys and being involved in services research, but reported a perceived lack of sufficient communication and research skills, and a lack of time.

Since competing commercial priorities hamper pharmacists' research involvement, separate research funding is an important facilitator. For surveys to include all eligible patients, services to be relevant for both practice and patients and to target the patients in most need of support with their medication, research collaboration with healthcare, other professions and across pharmacies is also necessary.

*Keywords:* Pharmacy, Community pharmacy, Pharmaceutical services, Drug utilization research, Survey, Patient, Pharmaceutical care, Feasibility, Sweden

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# Personal reflections

The introduction of the concept pharmaceutical care presents a milestone in the development of pharmacy practice (1) and for the past decades, there has been a shift from a dispensing and compounding focus towards a patient-centered focus, with provision of pharmacy services as a key feature (2).

Since practice research is important to generate evidence for new services, it is essential for the development of pharmacy practice (3). Pharmacy practice research can be divided in two main themes: research related to pharmacy as a data source and research related to the pharmacy as the object of research (4). To give a broad picture of recent and current community pharmacy research in Sweden, both themes are represented in this thesis, specifically studying pharmacy-based patient surveys in drug utilization research and pharmacy practice research related to the development of cognitive pharmaceutical services.

This topic evolved during several years, in a specific setting and a national context. The pharmacy-based patient surveys, conducted for drug utilization research purposes in the setting of the Swedish retail pharmacy monopoly indeed constitute a very specific research context. Since these surveys originally were offered as a commercial service to various stakeholders with interests in monitoring drug utilization, the scientific evaluation of the method was initially intended as a measure to describe and hopefully guarantee a certain level of quality in the conduct of the surveys and consequently also to assure validity of the data they generated.

My former role within the National Corporation of Swedish Pharmacies (Apoteket AB) as a project manager for the development of the pharmacy-based patient surveys and later for the marketing and conduct of the individual surveys came to include engaging in the scientific evaluation of the method, with a focus on different aspects of bias. When my involvement eventually narrowed to include only the scientific evaluation, I had become involved in a study on a community pharmacy-based intervention aiming at enhancing adherence to treatment in incident statin users, a study which is still ongoing. This coincided with a debate on why and how Swedish community pharmacies should demonstrate the value of their services through pharmacy practice research, similar to what is being done or has been done in several other European countries (5). Differing recruitment rates and diffi-

culties reported by the pharmacies contributing in the adherence study made it clear that certain conditions need to be fulfilled for successful pharmacy involvement in pharmacy-based research, not just conducting pharmacy-based patient surveys but also research on pharmacy practice itself.

In this thesis, the term feasibility refers to both the appropriateness of the setting (community pharmacies) and of community pharmacy staff as “research doers”. Pharmacy practice research is necessary for the development of cognitive pharmaceutical services. I therefore hope that this thesis will contribute to an increased understanding of the conditions required for successful involvement of community pharmacy staff in pharmacy-based research, and to evaluate the data generated through a certain type of research: pharmacy-based patient surveys on drug utilization.

## Included papers

- I Frisk P, Kälvemark-Sporrong S, Wettermark B. Selection bias in pharmacy based patient surveys. *Pharmacoepidemiol Drug Saf* 2014; 23:128-139.
- II Frisk P, Bergman U, Kälvemark-Sporrong S. Exploring community pharmacists' experiences of surveying patients for drug utilization research purposes. *Int J Clin Pharm* 2015; 37: 522-528.
- III Frisk P, Sporrong SK, Ljunggren G, Wettermark B, von Euler M. Utilisation of prescription and over-the-counter triptans: a cross-sectional study in Stockholm, Sweden. *Eur J Clin Pharmacol* 2016; 72 (6):747-54.
- IV Frisk P, Holtendal C, Bastholm-Rahmner P, Kälvemark Sporrong S. Competence, competition and collaboration: Perceived challenges among Swedish community pharmacists engaging in pharmaceutical services research. *Manuscript*.

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# Background

## Drug utilization research

Drug utilization research is a scientific discipline that aims to describe and understand the use of medicines in society. It began to develop in the 1960s, with the purpose of studying the rational use of drugs, and has continued to develop since (6). Ageing populations, increased disease prevalence, demands from healthcare consumers and the introduction of new drugs have contributed to increasing expenditure within the health sector over the last decades (7) and hence a growing interest in drug utilization studies and outcomes research.

Drug utilization research is defined as “an eclectic collection of descriptive and analytical methods for the quantification, the understanding and the evaluation of the processes of prescribing, dispensing and consumption of medicines, and for testing of interventions to enhance the quality of these processes” (6). Appropriate methods and a variety of data sources are essential when it comes to monitoring drug utilization.

Even though results from randomized controlled trials (RCTs) are considered the highest level of scientific evidence of an association between exposure and outcome (8) they do not necessarily reflect the effectiveness and safety demonstrated once a drug has been introduced in larger, unrestricted patient populations (9,10). Hence, observational studies of safety and effectiveness in these populations are of great importance.

Observational studies, including drug utilization studies, are either descriptive or analytical, depending on aim and level of complexity. They are often quantitative (Fig. 1), but qualitative methods are increasingly used to capture aspects of drug utilization that concern attitudes, experiences and subjective views of e.g. patients and prescribers (6). Descriptive drug utilization studies describe patterns of drug utilization, whereas analytical studies link drug exposure to outcome measures (6). They may either be designed to determine factors influencing drug prescribing (i.e. the drug is the outcome) *or* assess the safety or effectiveness of the drug.

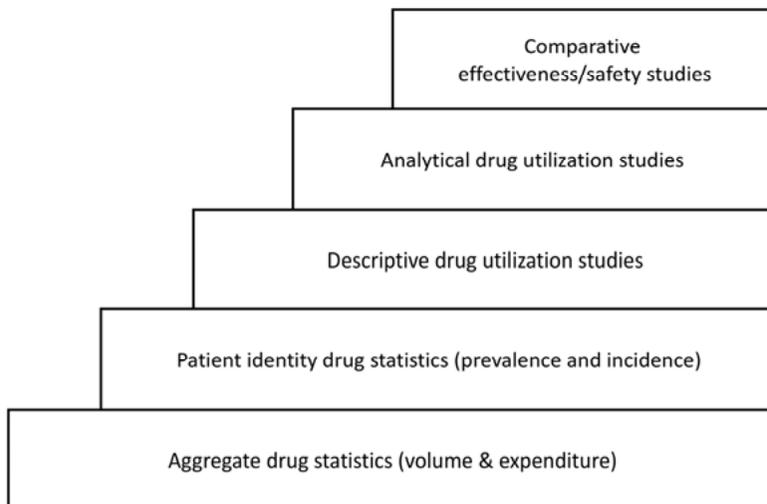


Figure 1. Drug utilization study types, with increasing levels of complexity (11). Reprinted with permission from Springer.

## Data sources in drug utilization research

A variety of data sources can be used in drug utilization research, depending on research question and choice of research method. Common sources include reimbursement and pharmacy dispensing databases, medical records, patient registries and patient surveys (6). Patient self-reported data collected through surveys are often collected for a specific research purpose, and are therefore called *primary data*. Data in medical records, pharmacy dispensing databases and patient registries are primarily collected for other purposes than research, and are therefore called *secondary data*. These data sources complement each other and allow flexibility in study designs (Table 1).

Large reimbursement and dispensing databases, such as the Swedish Prescribed Drug Register (12) are increasingly used in drug utilization research (6). They are considered to provide data representative of routine clinical care, at relatively low cost. By linking their data to other health databases and potentially to electronic medical records the association between drug exposure and clinical outcomes may be studied. The limitations of these databases include the lack of information on over-the-counter (OTC)-drugs, herbal drugs and other clinically relevant information. In some countries

they only contain data on drugs in the reimbursement scheme, not cheaper drugs paid by the patient (6). Despite the advantages of this type of databases, the data cannot reveal whether a dispensed drug actually is taken, and taken correctly.

Prescriber data from medical records normally contain the clinical information missing in reimbursement or dispensing databases. Several validation studies have however compared the drug information in medical records with the corresponding information reported by patients, and often found it to be discrepant (13–16). The increasing use of electronic health records (EHRs) has improved the accuracy and completeness of medical records, but uniform and complete records with a quality that allows extraction of reliable data for large-scale epidemiological studies are still rare (17). In addition to variations in data format, quality and completeness, the restrictions to data access imposed by legislation and policies of database holders, are challenging (18). Since an increasing number of new, expensive drugs are being introduced as in-patient treatments, it is urgent to find methods and tools for monitoring drug utilization in hospital settings (19).

Disease-specific patient registries with individual level data are increasingly used within healthcare and research, contributing with the clinical information missing in officially administered health databases (20). They contain a variety of clinical, laboratory and diagnostic variables, and some also contain patient self-reported data on quality of life, life-style and general health status. However, pharmacologic treatment is currently only documented in about one third of the Swedish registries and completeness regarding coverage of the target population needs to be improved (20).

One rationale behind patient surveys is the assumption that the patient ought to be the primary source of information in matters regarding his or her health, especially when it comes to their subjective view and experiences as users of healthcare services and drugs. However, the collection of self-reported data is often time-consuming and logistically complicated. Since patient surveys are based on samples and rely on patient recall, they are subject to both selection and recall bias, a threat to their validity (21). Nevertheless, patient self-reported data are frequently used in drug utilization research, either as a supplement to other data or when drug exposure data are validated, often with self-reported data as the “golden standard” (13,14,22–25).

The specific content of databases and patient registries varies both within and between countries, hence the feasibility of a certain data source should be assessed in a study specific context. Despite the flexibility of using surveys to complement other data sources, the reporting accuracy and data quality always depends on the respondents’ memory, knowledge, experience,

motivation and personality (26). Even cognitively well-functioning patients may e.g. have difficulties assessing efficacy/effectiveness and safety, depending on their knowledge, memory and pre-understanding.

Table 1. Advantages and limitations of individual level data sources in drug utilization data sources.

<b>Data source</b>	<b>Advantages</b>	<b>Limitations</b>
Reimbursement or pharmacy dispensing databases	Large Low cost of use Reflect routine care	Lack of data on OTC drugs, herbal drugs or drug purchases made abroad Purchase $\neq$ use
Medical records /Electronic health records (EHRs)	Clinical information Diagnoses Results from diagnostic procedures (Lifestyle) (Quality of life)	Varying in quality, structure and coverage Diversity of EHRs Technical challenges in data extraction
Patient registries	Disease specific Clinical information Results from diagnostic procedures (Lifestyle) (Quality of life)	Disease specific Often lacking drug information Completeness and coverage
Patient surveys	Primary data Patient's own information Attitudes, experiences Lifestyle Quality of life	Lack of health knowledge Recall bias Feasibility

## Pharmacy-based patient surveys

One of the themes of pharmacy practice research is research related to the pharmacy as a data source, and the use of pharmacies as settings for patient surveys on drug utilization is common. Patients are approached either for recruitment purposes only (27–30) or for actual collection of the data (31–37). In most studies, the pattern of use of the purchased drug is being studied. Other common topics are indication for use (32,33,35,36), occurrence of side effects (27–30,35), healthcare utilization patterns (31,34), concomitant medication (33), adherence (35,38) and patients' opinions about prescribing (39).

These examples come from eight western European countries, with varying degrees of regulation in the retail pharmacy sector, e.g. whether pharmacy chains and Internet pharmacies are allowed, and ownership regulations. The countries also differ regarding density of pharmacy retail outlets (40). Both paper and electronic questionnaires are used, probably depending on the technical infrastructure available.

Hence, there does not appear to be any single retail pharmacy system or characteristic that is associated with use of pharmacies as a setting for drug utilization surveys, other than a well-structured and regulated system. It is instead likely that countries with universal health coverage (41) and public funding of drugs have an increased interest in monitoring appropriate use of medicines, adherence to treatment guidelines and reimbursement restrictions, and that they therefore utilize all available data sources, including patient self-reported data collected in community pharmacies. In addition, pharmacy-based patient surveys are also conducted in some countries with a strong academic interest in pharmacy practice research (4,42,43).

In contrast to the different data sources available to study prescription drug utilization, studies on over-the counter (OTC) drug utilization rely on aggregate sales data and patient surveys only. Since postal as well as other type of population-based health surveys are known to suffer from declining response rates (44) surveying patients at the point of drug sales in pharmacies is an important way of finding respondents in selected patient groups.

### **Pharmaceutical policy in Sweden**

As in many other countries, an increasing interest in methods to monitor drug utilization has been seen in Sweden in the past 15–20 years, coinciding with key changes in legislation, administration and drug access. In 1997, it became mandatory for each county council to have a drug and therapeutics committee (45) and at about the same time the costs of prescription drugs within ambulatory care were transferred from the state to each county council (46). Prescription drug costs are largely covered by each county council, which in turn receive annual reimbursement from the government. A nation-

al scheme regulates patient co-payment (47). For cost containment reasons, generic substitution was introduced in 2002, alongside with legislative changes regarding pricing and reimbursement of prescription drugs, including the introduction of reimbursement restrictions based on assessments of cost-effectiveness (48). The establishment of the Dental and Pharmaceutical Benefits Agency (formerly the Pharmaceutical Benefits Board), and their role in drug cost-effectiveness assessments and reimbursement decisions resulted in a growing need for both national and regional drug utilization monitoring (49). Individual level drug utilization data from the Prescribed Drug Register were made available from July 2005, and have contributed significantly to pharmacoepidemiological research since then (50).

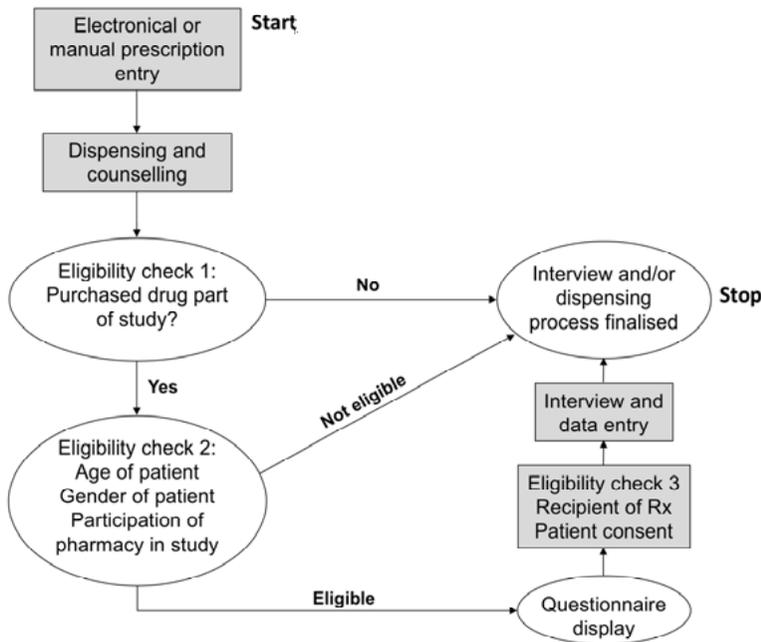
The retail pharmacy monopoly was founded in 1970 and allowed only the state-owned company the National Corporation of Swedish pharmacies (Apoteket AB) to provide pharmaceutical services to the whole country. It was abandoned in 2009 (51), and the years preceding this reregulation the former monopolist implemented several pharmaceutical services. These included medicine use reviews, academic detailing (university or non-commercial-based educational outreach), pharmacy-based health check-ups, and the two objects of study in this thesis; pharmacy-based patient surveys and recruitment to adherence support programs. Since the reregulation, the number of pharmacies has increased by 50% (52). The market is largely dominated by three pharmacy chains, covering 79% of the market (52).

### **Pharmacy-based patient surveys in Sweden**

The method by which the pharmacy-based patient surveys routinely were performed was developed to meet the increasing need for patient self-reported drug utilization data, regardless of purpose. The surveys were offered as a commercial service to pharmaceutical companies, authorities and others interested in monitoring drug utilization. The national, computer-based dispensing system facilitated the data collection at the pharmacy counter, since the surveys were conducted with computer-aided questionnaires integrated in the dispensing system, automatically retrieving some data from the prescriptions of the participating patients (53). Each patient meeting survey-specific entry criteria was offered a questionnaire at the end of the drug dispensing process (Fig. 2) and enrolled if a) he or she collected the drug for him- or herself and b) gave consent for participation. This eligibility check, labelled Eligibility check 3 in Figure 2, included steps a and b, and was done by the dispensing pharmacist, since the required data was not available in the prescriptions.

The pharmacies selected to regularly perform the surveys were evenly distributed across Sweden, based on an operative organization with 11 regions

and 5–7 selected pharmacies per region, with at most 72 pharmacies. However, they were not selected randomly, but instead selected based on how well they were performing operatively, as measured by waiting time for dispensing services. The rationale for this selection was that a pharmacy assuming extra tasks, such as survey data collection, must be productive and well-functioning in its delivery of standard services, to manage the extra workload.



*Figure 2.* The pharmacy survey process (53). Grey boxes represent activities performed by the dispensing pharmacist, transparent ovals represent process steps performed automatically by the dispensing system. Reprinted with permission from Springer.

The surveys were primarily targeting patients redeeming prescriptions for new, expensive drugs dispensed in community pharmacies. Their purposes varied but common aims of the surveys were to study either prescribers' adherence to prescribing or reimbursement guidelines (36), drug related issues relevant from a patient perspective (34,54) or prescribing issues relevant from a marketing and/or business development perspective. Common survey questions concerned indication for use, concomitant medication, previous drug treatment or other therapeutic or diagnostic interventions, OTC or herbal drug utilization, prescriber speciality and patient experiences of utiliz-

ing a specific drug. Data were collected as patient level data, facilitating calculations of distributions of basic patient characteristics such as age, gender and indication or indications for use. Since patient identifiers were not routinely collected, record linkage to other data sources was not performed, even though it was technically and theoretically possible. A typical questionnaire was short, with less than 10 questions on average, and the typical study was descriptive.

Depending on the requirements of the commissioners of data and study purpose, the surveys were categorized either as marketing research, quality monitoring or scientific research. Surveys planned to be published scientifically were always reviewed by an Ethical Review Board, as required by the Ethical Review Act (55). To meet the requirements of the commissioning companies, all surveys were performed according to the guidelines of the European Society of Opinion and Marketing Research, ESOMAR. These guidelines cover central ethical and other research-related aspects, including confidentiality, protection of respondent integrity, data safety, inclusion of children, adolescents and vulnerable individuals, as well as responsibilities towards clients, the general public and the research profession (56).

### Aspects of bias

The aim of the method presented above was to select representative samples of patients using a particular prescription drug, in order to draw general conclusions about this patient population. However, since random sampling was not applied, the samples did not represent the population (all patients using the drug under study) statistically (57). Therefore, bias was introduced.

In a research context, bias refers to the presence of systematic error in a study (8). Many specific biases have been described and several classification systems have been proposed (58,59). The most common distinguish between bias introduced by factors determining who is exposed in the population (confounding), who is included in the study (selection bias) and errors of assessment and measurement (information bias) (8,58). The distinction between selection bias and confounding is being discussed, particularly since confounding sometimes is being referred to as treatment-selection bias (59,60).

The general categorization shows that bias is specific for a specific study, and needs to be analyzed in the context of that study population (59). In any sample survey (or other study in which sampling has been done) there is a source population, representing all patients potentially eligible for inclusion, and a study population, representing those actually studied. Hence, the source population is the population from which the study population origi-

nated. If the results of a study are generalized, i.e. applied to a broader population, this is considered to be an extended population (58) (Fig. 3).

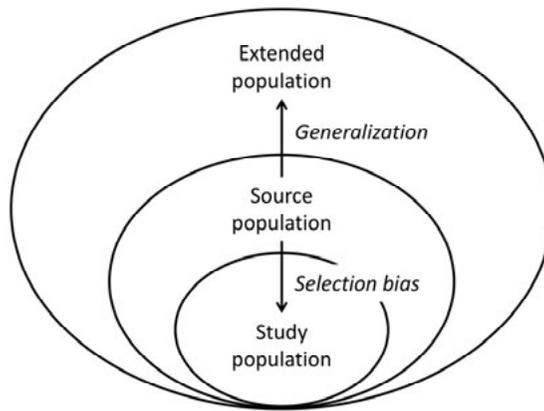


Figure 3. General relationship between study population, source population and extended population (58). Reprinted with permission from American Society of Health-System Pharmacists, Inc.

The different sampling steps in the pharmacy-based survey process represent patients who have received a prescription for a drug under study (extended population), enter a pharmacy participating in a survey (source population), are offered participation and consent to participate (study population). These steps introduce selection and information bias (Figure 4).

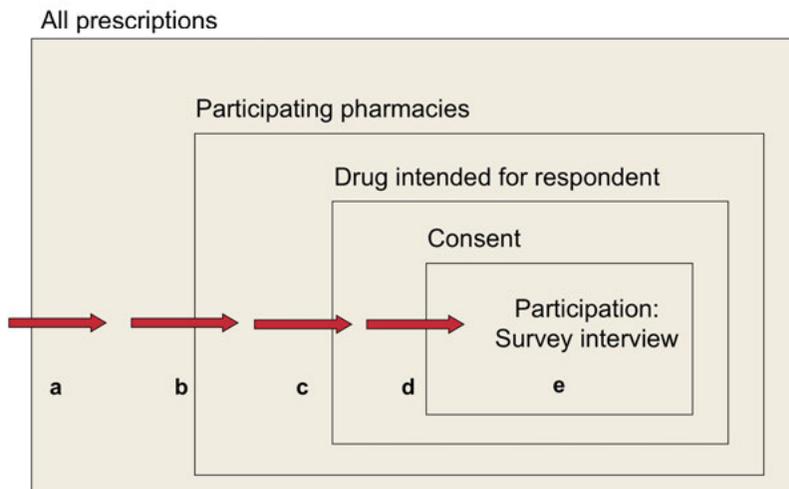


Figure 4. Process steps potentially affecting data validity. The types of bias introduced are a-d) selection bias, e) selection bias and information bias.

## **Selection bias**

Selection bias arises when the observed patients are not representative of the broader patient population of interest (8) and may be introduced by various mechanisms. Regardless of mechanism, the relevant general question when addressing selection bias is: *Why do some patients have complete data and others do not?* (60). In the context of the pharmacy-based surveys described here, this translates into: *Which patients are excluded on their way from receiving a prescription (and thus belonging to the extended population of interest) to participating in a particular survey?*

a) Selection bias in pharmacy-based patient surveys is introduced when a patient who is prescribed a drug does not redeem the prescription. This primary nonadherence may have several reasons, such as changes to drug therapy in emergency situations and duplicate prescriptions (61), but it may also be cost-related (62,63). Primary nonadherence is therefore likely to vary considerably between countries and co-payment schemes. The incidence is estimated to an overall mean of 16%, but the range is wide (0.5–52.4%), with large variations depending on e.g. method to assess nonfulfillment, disease, sample size and year of study (64). Since Swedish primary non-adherence rates are estimated to be low and mainly related to duplicate prescriptions (61), the impact of primary nonadherence on the selection of samples for the pharmacy-based patient surveys will not be included in this analysis.

This stage in the subject selection process also concerns drugs that are available as both prescription and OTC drugs, e.g. proton pump inhibitors and triptans. When the surveys are intended to reflect all use of the drug or drug groups, use of OTC purchases have to be captured e.g. by approaching customers in the self-service area of the pharmacy.

b) A survey on the use of angiotensin receptor blockers (ARBs) and prescribers' adherence to prescribing guidelines revealed a potential selection bias related to the fact that the patients selected for the pharmacy-based survey interviews were those collecting their prescription drugs themselves (36). Elderly women were underrepresented among study participants, and the survey sample differed significantly from all patients having an ARB prescription dispensed at the participating pharmacies during the same month (regardless of who redeemed it) as well as all patients having an ARB dispensed in any pharmacy during the same month. This indicated that the distribution of pharmacies in this particular study did not contribute to any age- or gender related bias, but that the selection of study participants in the participating pharmacies did.

c) The extent to which patients allow representatives such as relatives or healthcare personnel to collect their prescription drugs is rarely documented. When information is to be collected in the pharmacy, directly from the user of a drug, patients with physical disability or cognitive impairment, as well as younger children are more likely to be excluded. The impact of this selection probably varies considerably, depending on drug or therapeutic area (65). However, considering the general increase in drug prevalence with age there is a risk of exclusion of the oldest patients and a resulting healthy selection effect.

d) Even though high response rates are preferred, they do not automatically eliminate non-response bias (66). Non-response is a general and growing problem in health related surveys (44). It is not completely random, but involves age and marital status (67–70), as well as gender and educational level (68–72). People who refuse participation are generally younger, of male gender, less educated and unmarried and non-participation is also associated with poorer health (69–72).

e) When survey data are collected through face-to-face interviews, it is important that all interviewers are provided with the same interviewer instructions (e.g. on patient selection) and adhere to them (26,73). In addition, the setting must be suitable for interviews, offering enough privacy and time to complete the interviews properly (26,73).

### **Information bias**

Errors of assessment and measurement are referred to as information bias. In surveys, errors of assessment and measurement are multi-causal and involve the respondent, the potential interviewer and the questionnaire itself.

Recall bias, i.e. errors related to the respondents' difficulties to remember details about themselves, their conditions and treatments, is a common problem in health surveys (73). In drug utilization surveys, the requested recall time (74–77) as well as level of detail (75–77) and therapeutic group (74) have been shown to have an impact on reporting accuracy.

Discussing health related issues face-to-face with a healthcare professional may also be perceived as threatening to the respondents, potentially introducing social desirability bias. This is a significant problem whenever certain answers may make the respondent appear more or less responsible, well informed, self-controlled or successful (73). Measures to reduce social desirability bias in a survey include assuring respondent anonymity, offering different modes of questionnaire completion and adjusting question order, question structure and response options. The validity of data resulting from

threatening questions may be improved with data triangulation, i.e. using more than one method of data collection for the same data items (26).

To avoid information bias in interviewer-led surveys interviewers have to be provided with and adhere to standardized instructions on interviewing and how to handle questions related to the survey interview (73). Deviating from these instructions, either consistently or depending on respondent characteristics, may have an impact on the internal validity of the results.

## Pharmaceutical care in community pharmacies

The concept pharmaceutical care has been defined as “the responsible provision of drug therapy for the purpose of achieving definite outcomes which improve a patient’s quality of life” (1). It developed into a philosophy of practice, with the definition “a patient-centered practice in which the practitioner assumes responsibility for a patient’s drug-related needs and is held accountable for this commitment” (78).

Through the years, several definitions have been proposed and contributed in the discussion about what pharmaceutical care is, who can provide it, who the recipient should be, what activities that can be included and what the aim of pharmaceutical care is (79). A recent review by the Pharmaceutical Care Network Europe, aiming at redefining pharmaceutical care, suggests the broad but also specific definition “Pharmaceutical Care is the pharmacist’s contribution to the care of individuals in order to optimize medicines use and improve health outcomes” (79). It specifies that the pharmacist has a role in pharmaceutical care and that the final recipient is the individual patient, but allows both a variety of settings and the involvement of other health professions.

The operationalization of pharmaceutical care has contributed to the development and implementation of various care processes or services, provided either in hospitals, outpatient settings, or community pharmacies (80). When these services contain elements of information-giving, education and motivation, normally in addition to distribution of a product, they are labelled cognitive pharmaceutical services (CPS). CPS are defined as “professional services provided by pharmacists, using their skills and knowledge to take an active role in contributing to patient health through effective interaction with both patients and other health professionals” (81). Since pharmaceuticals are not mentioned, CPSs can include other than strictly drug-related services, e.g. disease screening.

A hierarchical classification of CPS has been suggested, in which services are classified based on clinical decision making and required change in pharmacists’ role and practice environment. Services range from information giving, requiring little or no change in the pharmacist’s role and practice environment, to prescribing, requiring shared or full clinical decision-making and considerable change in the pharmacist’s role and practice environment (Table 2) (82). The distinction between services provided in hospital or community settings (or both) is however not made in the classification, reflecting a necessary flexibility in choice of setting when services are planned, evaluated and implemented.

Table 2. Hierarchical model of cognitive pharmaceutical services (82).

Service	
1. Medicines information	
2. Compliance, adherence and concordance	
3. Disease screening	
4. Disease prevention	
5. Clinical intervention or identification of Drug Related Problems	
6. Medication use reviews	
7. Medication management/medication therapy management	<ul style="list-style-type: none"> <li>a. Home medication reviews</li> <li>b. Residential care home medication reviews</li> <li>c. Medication reviews with continuance follow up</li> </ul>
8. Disease state management for chronic conditions	
9. Participation in therapeutic decisions with medical practitioners	<ul style="list-style-type: none"> <li>a. In clinical settings</li> <li>b. In the pharmacy</li> </ul>
10. Prescribing	<ul style="list-style-type: none"> <li>a. Supplementary</li> <li>b. Dependent</li> </ul>

Community pharmacies have traditionally been product oriented, with dispensing of prescription drugs and sales of OTC drugs as their main source of income. The support for a shift from product orientation to service orientation has primarily come from the professional associations (83), but other stakeholders have also endorsed this transition as a way of optimizing the use of available resources in a healthcare system under pressure (84). Services intended to improve patients' knowledge of their medicines, adherence to treatment and clinical outcomes are indeed offered in community pharmacies in many countries (85–88), either by the pharmacies alone or in cooperation with healthcare, health insurers or private medication therapy management companies (85). A decade ago, the pattern of pharmaceutical care provision in Europe was reported to be related to the type of healthcare culture and -system (87) and there was, and still is, no consistent source of reimbursement (89). At that time, the Scandinavian countries, the UK (excluding Wales), Southern Europe and Central Europe were identified as areas with differing patterns of pharmaceutical care provision. However, several countries have recently implemented policies that support an expanded role for community pharmacists in chronic disease management, even though policy-relevant evidence is inconclusive (5,90). Services with reimbursement are e.g. the New Medicines Service (NMS) in England (91), the monitoring of patients with type 2 diabetes in Portugal (92), the Inhaler Technique Assessment Service (ITAS) in Denmark (93), medicine use reviews for asthma

patients (I-MUR) in Italy (94), medication reviews in Canada (95) and an asthma service in Australian community pharmacies (96).

As evidence-based policymaking is increasingly applied within the healthcare sector (90), a condition for funding CPS is strong scientific evidence, not only of the feasibility of a service for patients and providers, but clinical evidence of relevant therapeutic outcomes, and evidence of cost-effectiveness (3,97). To understand what promotes the sustainable delivery of services proven to be beneficial to patients and society, implementation research is also needed (98). This calls for strategies involving a range of stakeholders (82) and sufficient resources to conduct pharmacy practice and health services research, along with the implementation of services.

## Practice research in community pharmacies

Pharmacy practice research has been defined as “any research activity that pertains to pharmacy practice or patient care including, but not limited to, clinical and outcomes research, health services research and comparative effectiveness research” (99). Just as within hospital-based pharmacy, research in community pharmacy practice increased after the introduction of the pharmaceutical care concept, but has developed more slowly.

Studies on community pharmacists’ involvement in practice research indicate that research involvement was and still is a task outside of the ordinary for a community pharmacist (99). Perceived barriers and facilitators to research involvement exist on the individual level (the pharmacist him- or herself), the organizational level (the pharmacy/employer) but also on the patient level. On all levels, lack of time is the most frequently reported barrier to research involvement (99). This illustrates the commercial reality of most community pharmacies, but has also be suggested to represent a socially acceptable excuse masking deeper issues related to fears associated with modifying established work routines, and a perceived lack of value associated with research participation (100).

On the individual level, a perceived lack of competence is a frequently reported barrier to research involvement (101–104). Participating in formalized research training and having access to research specific support are therefore important facilitators (102–106).

The organizational level, represented by pharmacy management, is in itself important for pharmacists’ participation in practice-based research. Facilitating factors on this level are explicit support for research involvement, sufficient time for preparation and conduct of research (43,99,102,105) and adequate staffing to allow some pharmacists to maintain a research focus,

despite other competing priorities in the pharmacy (102,105–107). Sustainable involvement in research activities therefore requires additional funding (101,102,108).

In research activities involving recruitment of patients, evoking interest for participation among patients is reported to be challenging. Research-experienced pharmacists report that patients are reluctant to contribute to research, partly due to lack of time, but also because they do not expect to be recruited to a research project when visiting the pharmacy (105). Collaborating with local healthcare has been suggested as a means to enhance patient recruitment (105), in order to identify eligible patients but also to legitimize the pharmacy practice research projects among patients who primarily rely on advice from their caregivers.

There appears to be a general understanding regarding the importance and benefits of practice research, but far from all community pharmacists are willing to engage in research themselves. Depending on whether research-experienced or -inexperienced pharmacists are approached, reported rates of willingness to participate in research range from 19% to 84% (103,104,109–111).

## Pharmacy practice-based research networks

In the past two decades, community pharmacies have started to form pharmacy practice-based research networks (PBRNs) (112), with the purpose of facilitating the conduct of practice research and being a necessary link between pharmacy practice and academia (4,42,113). Practice-based research networks, regardless of whether they involve primary care, clinical or community pharmacy have some characteristics in common: Their organizations include at least a ten-fold of practices/pharmacies and their commitment should extend beyond a single research project (112). A community pharmacy practice-based research network has been described as a group of community pharmacy practice sites that are affiliated with an academic institution(s) that investigates questions related to community practice (114), a description that implies the importance of an academic institution devoted to pharmacy practice research.

As PBRNs engage in generating and collecting observational research data from “real-world” settings (112), they mirror the efficient collection of experimental data in multi-centre clinical trials. Community pharmacy research networks have been used to provide data in drug utilization studies (4,30,115), but also to study both feasibility and outcomes of pharmacy-based services (116–118). Sustainable involvement of both pharmacists and pharmacies in PBRNs is multifactorial, and involves obtaining funding, es-

establishing an appropriate network infrastructure, providing sufficient and relevant research training and feedback, as well as disseminating practice-based research findings (112). An important motivator for involvement is also research relevance for practice (4,114).

## Practice research in Swedish community pharmacies

Historically, research relating to Swedish community pharmacy practice has covered a range of topics, from broadly implemented pharmaceutical care-activities (119), the development of specific counselling models (120) and the detection and resolution of drug related problems (DRPs) (121,122) to the safety culture in pharmacies (123), a specific pharmaceutical care service (124), pharmacist-patient communication (125) and patient expectations of pharmacy encounters (126). Outcomes have included educational impact, detection and resolution rate of DRPs, reporting rate of dispensing errors, and communication content. Apart from an attempt to theoretically estimate the clinical and health-economic impact of detecting and resolving DRPs (121), no measurements of actual clinical and health-economic outcomes have been done.

In 2002, a counselling service inspired by the pharmaceutical care philosophy was introduced in a third of the Swedish pharmacies, and evaluated scientifically (127). The broad aim was to help patients make better use of their medication, which included explaining the purpose of each prescription or OTC drug and discussing expected effects and potential interactions. Practical use of the drugs could also be discussed, as well as topics relevant to address with the prescribing physician. The service could be initiated by the pharmacist or the patient. It was free-of-charge for the patients and the costs were covered with the overall margins for dispensed medications paid by the government. It was provided by certified pharmacists having completed additional communication training. Detected problems, advice given and actions taken were documented in a specific database. Even though some local prescribers could access this database for information purposes, prescribing physicians were not otherwise involved in the process.

This service was provided until 2009, mainly to older patients with multiple medications (128). Subjective outcomes reported by patients were an increased feeling of safety regarding their drug treatment and being better prepared for the next doctor's appointment (128), and similar to findings from the MUR evaluation in the UK (129), patients also found it hard to describe the service as separate from other healthcare experiences (130). Objective, clinical outcomes were however not evaluated.

Swedish community pharmacies recently piloted a cognitive service for asthma patients, similar to the services either pilot-tested or already offered

in other countries (93,94,96). Feasibility was found to be favourable, but clinical outcomes were not evaluated (131).

The reregulation of the pharmacy market in 2009 entailed not only structural changes of the market itself, but also a reduction and redirection of funds for social pharmacy and pharmacy practice research (132), with implications for individual researchers and academia as a whole. Hence, research in pharmacy practice is currently scarce.

The fourth study in this thesis was nevertheless initiated by Stockholm County council, the largest public funder of healthcare in Sweden. It constitutes a part of the scientific evaluation of a pharmacy-based intervention intended to promote medication adherence among patients initiated on statin therapy.

The intervention is a modified version of adherence support programs available in Sweden, commonly funded by the drug manufacturer. They often include pharmacy-based recruitment of patients initiating treatment with new on-patent drugs.

Since it is known that the largest drop in refill rate takes place as early as within the first months of initiation and that persistence is moderate (133), the intervention focuses on informing patients of the importance of adherence to statin therapy and removing barriers to adherence within 1-3 months after the first prescription is filled. The pharmacy involvement includes approaching patients in the pharmacy and offering them to take part, and if they agree, register them for the intervention. The pharmacies also receive the patients for a follow-up visit. Part of the intervention is provided by a team of nurses, and is largely managed from a call-center.

The design of this adherence program makes it similar to the New Medicines Service in England (91) and the TelCIP (Telephone Counseling Intervention by Pharmacist) in the Netherlands (134), both proven to have significant effects on adherence to lipid lowering treatment. Since the intervention will be evaluated in a research project, the pharmacists involved are by definition taking part in pharmacy practice research, and were therefore approached to share their experiences in a feasibility study.

# Aims

The overall aim is to contribute to an increased understanding of the conditions required for successful involvement of community pharmacists in pharmacy-based research, and to evaluate the data generated through a certain type of research: pharmacy-based patient surveys on drug utilization.

The specific aims of the four included studies are

- I. To evaluate if there is a selection bias in drug utilization surveys on prescription drugs conducted in Swedish community pharmacies, to describe the direction of this potential bias and discuss the implications to the results.
- II. To explore the experiences of the pharmacists involved in pharmacy-based patient surveys and to explore a potential random or systematic exclusion of eligible patients, as well as finding areas of improvement to the process of performing structured survey interviews at the pharmacy counter.
- III. To describe prescribing patterns and OTC use of triptans in Sweden, with a focus on the history of migraine diagnosis, concomitant antimigraine medication, and contraindications for triptan use.
- IV. To explore the pharmacists' experiences of participating in an ongoing research project evaluating a pharmacy-based adherence-promoting pharmaceutical service in Stockholm, and to explore their views regarding future participation in practice research aiming at developing cognitive pharmaceutical services.

# Methods

## Paper I

### Data collection

This study included a majority of all surveys conducted during 2006-2012 with the method described in figure 2. All drugs were classified according to the version of the Anatomical Therapeutic Chemical (ATC) classification system in use at the time of the study (135). The surveys were selected based on the following criteria:

- The surveys should be completed, i.e. surveys ongoing at the time of the study were excluded.
- For calculation of the relative sample size of each survey, dispensing data from 2010 of the Swedish population should be available in the Prescribed Drug Register. To provide survey samples likely to be representative of all users of the specific drug in question, the number of responders in each survey should constitute at least 0.5% of the period prevalence rate of 2010 for the corresponding drug, ATC fifth level.
- To avoid duplicate registration of patients in each study, the surveys should only include one pharmacological group, ATC fourth level.
- Population dispensing data from 2011 in the Prescribed Drug Register should be available for calculation of current age distribution within each selected drug group, ATC fifth level.

Age- and gender distributions among patients eligible for the surveys were compared to the age- and gender distribution of all Swedish patients, receiving the same drug or drugs during the same or approximately the same time period, as given by the Swedish Prescribed Drug Register. The age categories used were 0–44 years, 45–64 years, 65–74 years and >75 years. When applying the general relationship between populations to this study (Fig. 3), the Prescribed Drug Register represents the extended population of each survey, whereas the data on patients eligible for surveys serve as a proxy for the study population.

## Analysis

The differences between the proportions of patients within the age and gender segments of each pair of survey/dispensing data were calculated. Proportions with non-overlapping confidence intervals on the 95% level of confidence were considered statistically significant (136).

## Paper II

### Data collection

In this mixed methods study a sequential explanatory design (137) was used to explore community pharmacists' experiences of surveying patients for drug utilization research purposes. The pharmacists conducting the pharmacy-based patient surveys were instructed to interview all patients passing the eligibility checks 1-3 (Fig. 2). To establish if this instruction was followed or if there was a potential interviewer induced selection bias and the reasons for this potential bias there was a focus on pharmacists' perceived feasibility of interviewing patients at the pharmacy counter and its effect on pharmacists' behaviour.

Two methods were used:

- 1) a web-survey distributed to all dispensing pharmacists at the 72 pharmacies regularly conducting patient surveys;

- 2) semi-structured telephone interviews conducted with a sample of the pharmacists. In both survey and interviews, the pharmacists were asked to think back on their past five years of experience.

- 1) An anonymous semi-quantitative survey questionnaire, covering the experiences of the interviewing pharmacists was e-mailed to the pharmacies, to be further distributed to all dispensing pharmacists, approximately 400 respondents. Data were collected during two consecutive weeks (28 Oct - 11 Nov 2011).

The survey was designed to explore how the pharmacists perceived the different steps preceding the data collection, as well as the data collection itself. The survey included the following items: positive and negative experiences of interviewing (open-ended questions), general perceptions on questionnaire length and optimal questionnaire length (closed-ended questions) and whether the pharmacists avoid interviewing eligible patients (closed-ended question). In the estimations of questionnaire length, the number of questions was regarded as a proxy for the time required for interviewing.

2) Based on the initial results from the survey, an interview guide was developed outlining three main areas: The preparation and training process, the patient-pharmacist encounter and personal reflections and strategies regarding interviewing patients as part of the drug dispensing process (Appendix I). Purposive sampling (26) was applied to obtain a sample of pharmacists as experienced in interviewing as possible. Twelve pharmacies were selected based on their extensive involvement in pharmacy surveys. Each pharmacy manager was then asked to suggest pharmacists for the interviews. The interviewees were informed about the study by e-mail before the interview. The interviews were conducted by a pharmacy graduate student, who had some general experience in working in community pharmacies but had not been involved in any pharmacy surveys. They were conducted as semi-structured telephone interviews (26) during Nov-Dec 2011, and lasted approximately 15 minutes. During the interviews, extensive notes were taken and findings were summarized in writing afterwards.

## Analysis

The results of the quantitative and qualitative parts of the study were integrated in the interpretations phase of the study (137). The closed-ended questions in the survey were analysed descriptively. The answers to the open-ended survey questions were coded according to their content. The interviews were independently analysed by the two first authors, respectively, using descriptive content analysis (138,139). The main areas in the interview guide served as deductively decided data categories, whereas data reported within each of these categories were categorized inductively. The results arrived at were compared and differences were discussed until consensus was reached.

## Paper III

### Data collection

This cross-sectional study, based on dispensing data covering prescription triptans and survey data covering OTC triptans, aimed at describing utilization patterns of prescription and OTC triptans in Stockholm, Sweden. A secondary aim was to explain an observed increase in sales of prescription and OTC triptans (140), following the market introduction of OTC triptans in Sweden in 2006.

1) The database study included all incident individuals purchasing prescription triptans in 2014. Being incident was defined as having at least one pre-

scription of triptans dispensed in 2014 and none during Jul 2010-Dec 2013. The data source used was the Stockholm County Council healthcare data warehouse VAL, which contains information on all consultations in primary and secondary care (defined as specialist outpatient care), and all hospitalizations (141). The regional data warehouse also contains the same data on prescription drugs as the Prescribed Drug Register, but the coverage is restricted to the residents in the region. Data on triptan use, concomitant use of other drugs for acute migraine and drugs for prophylactic treatment were linked to data on migraine diagnosis and contraindications.

2) A survey, distributed by observers to patients purchasing OTC triptans in three pharmacies in Stockholm, was conducted to capture the proportion of patients who a) had been diagnosed with migraine by a physician, b) had a history of prescription triptan use, c) were alternating between or combining prescription and OTC triptans, d) experienced migraine attacks with a frequency that could justify prophylactic treatment and e) received prophylactic drug treatment for migraine. It also captured f) concomitant use of other analgesics or antimigraine drugs, if any, and g) to what extent patients who purchased OTC triptans actively were offered help or counselling by pharmacy staff (Appendix II). The participating pharmacies, two in the center of Stockholm and one in a large mall in a densely populated suburban municipality, were selected based on their supposed sales volumes of OTC triptans. The observers were present in the pharmacies during daytime, at differing hours all days of the week, approximately 5-6 hours per occasion.

The respondents were offered to either have the questionnaire completed by the interviewing observant, complete it themselves while remaining in the pharmacy or have it sent by email for later completion.

## Analysis

Recruitment rate was measured as patients per sold packages during the study period. Descriptive statistics, such as numbers and proportions, were used to describe the study cohorts and the utilization patterns, with 95% confidence intervals (95% CI) where appropriate. Analyses were stratified by sex and age in the categories 0–11 years, 12-18 years, 19-44 years, 45–64 years, 65–74 years and >75 years. These were based on one of the intervals for population statistics recommended by the WHO and adjusted to also capture potential prescribing to children and adolescents. Means were presented with standard deviations (SD). Associations between categorical variables in both survey and dispensing data, respectively, were analyzed using Pearson's chi-square tests. Two-sided p-values <0.05 were considered significant.

## Paper IV

### Data collection

Data were collected in focus group interviews (FGIs) (142), with pharmacists representing five of the 67 pharmacies participating in the project. The invitation to participate was sent to 39 pharmacies, selected to represent pharmacies with low, medium and high levels of recruitment to the pharmaceutical service being evaluated. A semi-structured interview guide was developed, covering knowledge/information about the cognitive pharmaceutical service (CPS) itself, the feasibility of the pharmacists' part of the CPS in the regular workflow in the pharmacy, including potential areas of improvement and views on research in general, particularly on involvement in pharmacy practice research (Appendix III). The interviews were held at four of the pharmacies during January and February 2017. The first author moderated the interviews and the second author was present as an assistant moderator and took notes. The interviews were audiotaped and transcribed verbatim. After the first two FGIs, the interview guide was slightly modified to also include questions regarding collaboration between pharmacies and healthcare and between different retail pharmacy chains, respectively. During the interviews, probing and follow-up questions were used in order to get deeper knowledge about the participants' experiences and views.

### Analysis

The data were analyzed using conventional content analysis (143), guided by the Consensual Qualitative Research method (144). The initial analysis was performed by the first and last authors, who independently and repeatedly read all transcripts and interview notes and inductively arrived at domains sorted under the two aims of the study. In two consensus sessions, further categorization of the domains into core ideas was done. During the consensus discussions, it became clear that all core ideas were shared by the two aims. This was because the majority of FGI participants had no experience of practice research other than the current pilot intervention and their views regarding future research participation mainly reflected their experiences in the ongoing project. Therefore, the results were reported together for both aims. In a cross-case analysis, the data represented by the core ideas were clustered into categories and subsequently interpreted (Figure 5). This was a continuous process, involving the first, third and last authors.

At the end of the analysis, the second author served as an auditor, checking that the results were based on the data and that no important data were overlooked. Quotes from the focus groups were used to exemplify the categories.

## Ethics

Swedish regulations specify under which conditions approval from an ethical review board is required in research involving humans (55). These include studies in which the participants are subjected to blood sampling, surgical procedures or other physical interventions, or when research methods are used that may affect the subjects mentally or emotionally. Included are also all studies in which the collected data represent sensitive personal data, as defined by the Personal Data Act (145).

Consequently, studies I, II and IV did not require approval by an Ethical Review Board. Nevertheless, ethical requirements were met. Informed consent was obtained and the respondents'/participants' anonymity was secured.

Study III was reviewed by the Ethical Review Board in Stockholm, and approved, with approval numbers 2014/788-31/2 and 2015/619-31.

# Findings

## Paper I

The surveys selected for this study were in most cases targeted at patients receiving drugs that were recently introduced on the Swedish market. They were intended to be used to study prescribers' adherence to reimbursement restrictions/prescribing guidelines, other aspects related to prescribing and/or actual drug use (e.g. daily dose taken by the patient, recommended dosing scheme and indication for use) or aspects related to the market introduction of the drug.

Out of the 45 surveys that had been conducted by the time of the study, 31 were included. In 25 (81%) out of these surveys, patients aged 75 years or older were significantly underrepresented, most likely because they did not appear at the pharmacy to collect their drugs themselves. This finding appeared across all therapeutic groups included in the study, but was most consistent within asthma/COPD and neurology/psychiatry, where it appeared in all included surveys.

The six surveys where this underrepresentation of the oldest did not occur either had a very small sample size, or concerned long-acting insulins or TNF- $\alpha$ -inhibitors. Data on women showed similar results as overall survey data, whereas the underrepresentation of the oldest age group among men appeared in a lower proportion of the surveys, 67%. This illustrates how surveying in pharmacies contributes to a general selection towards healthier survey samples, and that the consequences in individual surveys vary, depending on what drug is being studied.

## Paper II

In total, 176 pharmacists (about 44 %) completed the questionnaire. Out of these, 50 considered themselves to lack the experience necessary to complete the questionnaire, resulting in 126 actual respondents and an effective response rate of approximately 32 %.

A majority (82%) reported positive experiences of interviewing. The most commonly reported positive perceptions were that structured survey interviews make the patient feel important and improve the patient-pharmacist dialogue, reported by 18 (14 %) and 23 (18 %) of the respond-

ents, respectively. A majority (63%) also reported negative experiences, related to a perceived lack of time for interviewing, including increased stress when dispensing and the perceived effect of the survey interviews on patients' waiting time.

The general length of the survey questionnaires was considered appropriate by 83 % of the respondents, while 17 % felt they typically were too long. When asked to specify the appropriate number of questions for a survey performed at the pharmacy counter, one-third answered no more than five, and half no more than seven. None of the respondents thought that 11 questions or more were appropriate.

Almost half of the pharmacists (44%) admitted that they occasionally avoided interviewing eligible patients, due to the immediate increase in workload.

The interviews, conducted as telephone interviews with 19 pharmacists experienced in surveying, allowed pharmacists to elaborate further on their experiences. They perceived themselves to be adequately trained to perform survey interviews, and well enough prepared by means of the information provided before each study start.

Pharmacists perceived that patients generally reacted in a positive manner towards the offer to participate in a survey. In addition to the data generated as the primary goal of surveying, secondary benefits such as an improved patient-pharmacist dialogue and an increased detection and resolution of drug related problems were reported.

The dominating negative experience was the increase in workload, a common reason for excluding eligible patients. The reported perceived lack of time concerned both pharmacists and patients. Other reasons for excluding patients were actual or potential communication difficulties and the individual pharmacists' perceived competence. Patients not speaking Swedish or having an insufficient understanding of spoken Swedish, or patients with cognitive impairment were excluded.

Not being able to predict and prepare for the questions potentially elicited by the survey interview made some pharmacists avoid including patients all together. This finding, reflecting a reluctance to leave the familiarity of the dispensing "script" and rely on one's professional competence, is particularly notable, considering the similarities between structured survey interviewing and structured general counselling. The limited availability of staff resources was the most apparent area in need of improvement.

## Paper III

In the database study, 52% of the patients had a recorded diagnosis of migraine, 48% had no other acute treatment than triptans, preventive treatment was rare (12%) and contraindications were found in 2% of the patients.

The survey was conducted in September and October 2014 and included 49 patients, out of which 27 (55.1±13.9%) were women. This corresponded to an estimated response rate of 7%. A majority (63.3±13.5%) had been diagnosed with migraine by a physician and the same proportion reported current or previous prescription triptan use. A minority of the patients (12.2 ± 9.2%) were currently switching between prescription and OTC triptans or combining them. About half of the patients (53.3 ± 14.6%) reported having migraine attacks more frequently than twice a month. According to recent guidelines (146), patients who experience migraine attacks this often should be offered migraine prophylaxis, but only one out of ten patients (4.4 ± 6.0%) reported that this was the case. A majority (59.2 ± 13.8%) reported that they always or often are offered help or counselling when purchasing OTC triptans.

The combined results from the survey and the database study indicated that the previously identified increase of prescription- and OTC triptan sales results from increased prescribing to patients seeking healthcare and, independently, access to pharmacy-only OTC triptans to patients with previous use of prescription triptans, mainly preferring to self-medicate rather than adding OTC triptans to a therapy with prescription triptans. Current prescribing of triptans is done with attention to safety but poor recording of migraine diagnosis. The low prevalence of preventive therapy concerns both OTC and prescription triptan users and is consistent with results from other studies (32,147–149).

## Paper IV

Four focus group interviews were held with 18 pharmacists from five of the pharmacies involved in the project. The four domains identified were the service itself, operative conditions, the pharmacists' role/profession and other stakeholders and patients, respectively (Figure 5).

A common concern was how to communicate about the CPS with patients, both when recruiting and conducting the follow-up visits. Operative conditions were perceived as hampering research activities. As in previous research regarding community pharmacists' participation in pharmacy-based research, identified barriers to full involvement included lack of time, resources and staff, in addition to insufficient communication and research skills (99,102).

The competition between pharmacy chains was perceived as a barrier to continuity of care. Collaboration with healthcare, other professions and other pharmacy chains was identified as important for both community pharmacy services research and provision, making services more relevant for practice and patients, increasing the trustworthiness of pharmacy-based services research and implementation, and reducing the workload of pharmacists. Collaboration was however also regarded as threatening to the commercial interests of individual pharmacies and the pharmacist profession.

Successful community pharmacy services research and provision will require a stronger patient-centered perspective among all stakeholders, including the pharmacists themselves.

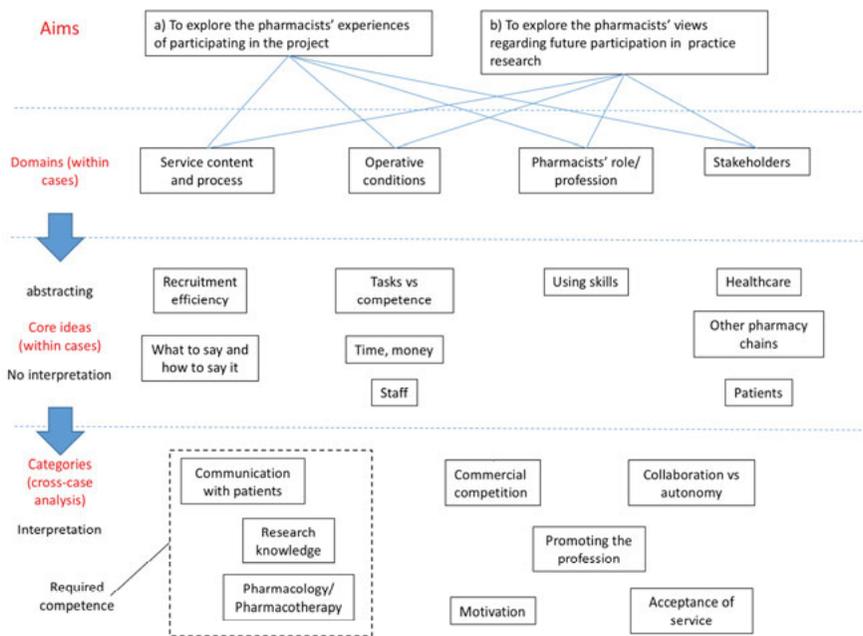


Figure 5. Data analysis model and overall findings in study IV.

# Discussion

Community pharmacies are an important source of data regarding drug utilization, both data generated automatically when drugs are purchased from wholesalers, prescription drugs are dispensed and OTC drugs are sold, and data collected in different types of surveys. In many countries community pharmacies are commonly used for surveys on drug utilization, often focusing on data that are too difficult or expensive to acquire from other sources. A major strength is the convenient access to patients, but just as in any other setting, large-scale surveys are logistically complicated.

With their large number of patient contacts, an obligation to dispense prescription drugs and make sure patients know how to use their drugs, and a shared infrastructure for electronic prescriptions, Swedish community pharmacies have the potential to contribute to pharmacy practice research. The studies included in this thesis contribute to an increased understanding of the conditions required for successful involvement of community pharmacy staff in pharmacy-based research, and help understand the strengths and weaknesses of data generated through pharmacy-based patient surveys.

Surveys on prescription drugs can be used to monitor actual use of both new and established therapies. Despite the methodological limitations with pharmacy-based surveys on OTC drug utilizations, it remains one of very few methods to compare the actual use of OTC drugs with the intended use. Services aiming at improved adherence can be offered at the pharmacy counter, either as part of a research project or as implemented services. The feasibility of Swedish community pharmacies as a research setting is however influenced by patients' direct access to pharmacy dispensing services and the duality of community pharmacies, being neither a fully commercial actor nor a fully established part of healthcare.

# Implications for pharmacy-based surveying and pharmacy services research

## The community pharmacy as a research setting

In this thesis, two mechanisms were detected, by which patients recruited at the pharmacy counter may be excluded from research participation when redeeming their prescriptions: Certain patients, particularly among the elderly, are underrepresented in pharmacy-based surveys because they do not visit the pharmacy themselves and instead have a representative redeem their prescriptions (paper I). In addition, dispensing pharmacists sometimes refrain from offering survey participation to patients perceived as complex because of e.g. age, language barriers and polypharmacy, to avoid a perceived immediate increase in workload (paper II). These mechanisms are both introduced in the process when the pharmacists check the eligibility (Figures 2 and 4). Both of them are likely to contribute to a healthy selection effect in pharmacy-based surveys, and services research and provision not fully reaching those who are in most need of support with their medication.

The systematic exclusion can, to some extent, be measured with national or regional dispensing data, an important measure to estimate generalizability. The extent and nature of the deliberate exclusion by pharmacists is however less measurable and therefore a greater threat to the validity of both surveys and services research. However, when the reasons for bias are known, it can be prevented or adjusted for.

Most surveys target respondents reporting on themselves. In some cases, it can be useful to allow a person close to the actual respondent to do the reporting (150). However, good reporting by representatives requires that he or she is close to the respondent and can both observe and discuss the matters that are to be reported. Current research on this type of reporting also indicates that this can be used reliably only within certain domains or index scores (151,152) and with certain question types (151). Considering the declining response rates in health-related surveys in general (44,153) and the fact that older patients are underrepresented in pharmacy-based patient surveys (paper I), allowing representatives to report could be considered when this method and setting is being used. Combining pharmacy-based surveys with surveying in other settings, e.g. healthcare centers, and oversampling in certain age groups can also be a way to reduce the effects of the systematic exclusion.

## Community pharmacists as researchers

The pharmacists' experiences of surveying (Paper II) or participating in other pharmacy practice research (Paper IV) add to the existing literature (99,102,105,154) on barriers, facilitators and improvement areas. Lack of time and resources are the most commonly reported barriers. Recruitment to and/or involvement in other services and services research (Paper IV) and surveying (Paper II) appear to be regarded as something to engage in when the workload permits it. Additional resources are therefore important for research tasks to be considered equally important as dispensing and sales of products. It is however relevant to consider if the perceived lack of time reflects an actual lack of time. Cvijovic and colleagues found that lack of time for research participation was provided as a socially acceptable excuse, that masked deeper issues related to fears associated with changing established routines among Canadian community pharmacists participating in a research study (100).

It also represented a perceived lack of value associated with research participation. In line with several studies on pharmacists' opinions on or experiences of research participation (99,102,106,110,155,156), the participants in paper II and IV recognize the importance of practice research for professional and practice development, but confirm that not all pharmacists share this positive attitude.

Negative attitudes, not only to the object of research (pharmacy-based surveys or services research) but to research in general, are indeed difficult to capture since they are subject to social desirability bias. When these attitudes translate into low motivation, they can contribute to poor interviewing and thus introduce information bias (Figure 4), in addition to the detected selection bias.

Trying to capture community pharmacists with a positive attitude to research, and allowing them to specialize, instead of engaging all pharmacists, could potentially be a way forward. At a time when pharmacists' level of involvement in practice research still was low (99), the Pharmacy Practice Research and Development Task Force in the UK stated that all pharmacists should be "research users", i.e. work according to documented best practice, and 10% of the pharmacists should be "research doers", i.e. actively involve in data collection and/or participate in evaluations of new services or models of service delivery (42). Considering pharmacists' reported rates of willingness to participate in research (103,104,109–111) and the perceived reluctance among some pharmacists (Paper II, Paper IV), this still appears to be a reasonable ambition.

## Development of pharmacy-based research networks within community pharmacy

With the existing infrastructure and a market dominated by three pharmacy chains, the logistical and technical requirements for establishing large research networks are fulfilled in Sweden. However, since current academic research in social pharmacy and pharmacy practice is scarce (132) the necessary support from and continuous collaboration with academia for developing and maintaining a PBRN is currently lacking. Since a basis within or close collaboration with academia is important for successful PBRN development and for practice research (4,42,113), this is a cause for concern.

In a recent governmental investigation, it was suggested that general pharmacy research funding should be redirected to social pharmacy (132), and that The Swedish Academy of Pharmaceutical Sciences should coordinate a group representing pharmacy chains, professional organizations, academia and healthcare, collaborating to strengthen community pharmacy-based research. These measures can potentially facilitate both the establishment of PBRNs and future research projects, relevant for practice.

## Implications for pharmacy education and pharmacists' role development

With increasing access to data from mandatory dispensing databases (157), pharmacy-based patient surveys can constitute a supplement to studies based on reimbursement or pharmacy dispensing data. Linking survey data to other types of individual level data however requires a scientific research purpose (145), and scientific research procedures to be performed, procedures which dispensing pharmacists prefer to leave to others because of perceived time constraints, lack of research knowledge and communication skills (Paper IV). Using Swedish pharmacy-based patient surveys in larger research studies, potentially linking survey data to other types of individual level data, will therefore require more research training among Swedish community pharmacists, as well as additional pharmacy staff.

Another aspect which is important to include in pharmacy curricula to promote future involvement in services research and provision is inter-professional collaboration (Paper IV).

These findings are primarily relevant for those within academia, who are responsible for pharmacy curricula improvements, but also to pharmacy owners and professional organizations. Providing research training, not only to undergraduates but also to practicing community pharmacists may increase the will to participate in research activities and build research capacity for future projects (155).

The pharmacists themselves and the pharmacy owners should consider who is responsible for developing the profession. It is the pharmacists who regard themselves as overqualified for their current tasks and desire another, more patient-oriented role (Paper IV). However, Swedish community pharmacists appear to have adopted a passive position regarding role development, similar to the attitudes expressed by Norwegian chain pharmacists (158), and handed over the responsibility to others, mainly their employers. On the other hand, one could argue that pharmacy owners are aware that participation in research resulting in reimbursed services will generate not only income but also satisfied customers and employees.

From the perspective of the pharmacist profession and community pharmacy as a retail actor, developing CPSs through research currently appears to primarily be either a matter of developing a profession or making profit through increased customer loyalty (102,106).

The need for practice-based research in community pharmacies, to support the development of reimbursed services, is ultimately a question of patient benefit, and services reaching larger patient groups. In 1990, Hepler and Strand challenged both the profession and relevant stakeholders when they concluded that “It is not enough to dispense the correct drug or to provide sophisticated pharmaceutical services; nor will it be sufficient to devise new technical functions. Pharmacists and their institutions must stop looking inward and start redirecting their energies to the greater social good.” (1). Twenty-eight years later, this still appears to be highly relevant.

## Methodological considerations

### Quantitative methods

#### **Study I**

In the data analysis, data from the Prescribed Drug Register are compared with survey data on all patients eligible for inclusion and redeeming their own prescriptions in the pharmacies involved. The discussion about the consequences of the detected selection bias is therefore simplified since it assumes that the age- and gender distributions of all eligible patients are the same as for all respondents. However, a high response rate among those eligible for participation indicates that the differences in age- and gender distribution between eligible patients and respondents most likely are minor.

#### **Study II**

The low response rate of the pharmacist survey is possibly related to how the questionnaire was distributed. Since it was sent anonymously as a survey

link to each pharmacy and forwarded to each pharmacist, the exact response rate is unknown and the possibility to describe either respondents or non-respondents is lacking.

### **Study III**

Since Swedish drug sales data are not publicly available on a pharmacy and product level, it was not possible to assess the appropriateness of the selected pharmacies in terms of OTC triptan sales. The use of external observers instead of regular pharmacy staff limited the number of hours that the self-service areas could be covered, and probably reduced the response rate. Self-reported migraine diagnosis, previous prescription triptan use and use of other migraine treatment could not be validated, since these data could not be linked on an individual level to the respondents' dispensing data.

## **Qualitative methods**

### **Study II**

The 19 participants had been selected by the pharmacy managers at the 12 pharmacies identified as having been extensively involved in surveying and the pharmacy managers identified the individuals to be interviewed. This purposive sampling may have introduced a bias, with positive attitudes and experiences being overreported. As the question about excluding patients can be perceived as measuring job performance, it is also likely that this behavior is underreported. The individual interviews gave similar responses, and a perceived saturation was achieved after about 8-10 interviews. Even though individual interviews have certain advantages (159), focus group interviews with pharmacists probably would have elicited both broader and deeper information and revealed potentially conflicting positions among pharmacists (142).

### **Study IV**

Small focus groups are easier to host, more comfortable for participants and facilitate recruitment, but the reduced size can limit the range of reported experiences (142). Considering the difficulties to recruit to the focus groups, all pharmacies participating in the project should have been invited. This could also have increased diversity, with pharmacists from more pharmacies participating and potentially sharing other experiences.

The moderator of the focus groups had previously been involved in both pharmacy-based surveying and recruitment to adherence support programs and therefore had personal opinions on barriers/facilitators to research in Swedish community pharmacies. The potential impact of this bias was however minimized through a) the use of the semi-structured interview guide, b) the presence of the assistant moderator and debriefing sessions after each

interview, c) the recording and transcribing of interviews, d) the consensual analysis process and e) auditing.

## Limitations

The studies included in this thesis are conducted in Swedish community pharmacies only, during a time when the Swedish pharmacy market changed considerably. Even though community pharmacies share many characteristics worldwide, it is difficult to generalize the results to other countries or contexts.

The drugs studied in paper I were all new on the market at the time of the surveys and it is therefore not possible to generalize the findings to all drugs or drug groups. The sample size of the surveys is mostly based on convenience sampling, not on statistical power calculations. Nevertheless, the results in paper I are consistent across therapeutic groups, despite the small sample size of some of the surveys.

The design of the adherence support program referred to in paper IV did not involve cooperation with local healthcare, even though this is a frequently reported facilitator in pharmacy-based research and/or service implementation (105,160,161). The reasons were a) the established design of the adherence support program, not involving other healthcare staff than those at the call-center, and b) the distribution of pharmacies and healthcare centers in the county of Stockholm. Stockholm is a densely populated county with 23% of the Swedish population (162), the highest number of community pharmacies of all counties and 13 pharmacies per 100 000 inhabitants (52). With 99% of all prescriptions being electronic and thus accessible for all pharmacies (163), the patients can redeem their prescriptions at any pharmacy, regardless of where they visited healthcare. Cooperation with local healthcare in a design where the pharmacies were the point of recruitment was therefore not feasible.

Paper III represents a case of pharmacy-based surveying, with a clinical instead of methodological research question. The methodological knowledge gained regarding pharmacy-based surveying is therefore implicit, and includes the difficulties of calculating response rates in a setting where the drug under study is an OTC drug kept in the self-service area of the pharmacy. To capture as many as possible of potentially eligible customers, it is advisable to involve all pharmacy staff in that type of data collection, not a few external observers, particularly when considering the generous opening hours of most community pharmacies in Sweden.

# Conclusions

Swedish community pharmacies have the potential to be a part of pharmacy practice research. The feasibility of using community pharmacies as a research setting and dispensing pharmacists as researchers is however affected by patients' direct access to pharmacy dispensing services and pharmacists' perceived conflict between achieving commercial goals and creating scientific evidence.

In surveys or services research conducted in Swedish community pharmacies, with the dispensed drug as the trigger for inclusion, an exclusion of patients who do not visit the pharmacy themselves makes patients, aged 75 years or older, underrepresented. Due to their perceived workload, dispensing pharmacists sometimes exclude those patients from research, who are perceived as complex or time consuming due to e.g. age, polypharmacy or difficulties with language. These mechanisms contribute to a healthy selection effect in community pharmacy-based surveys, and services research and provision not fully targeting those who are in most need of support with their medication.

Community pharmacists perceive themselves to be adequately trained for surveying, but lacking competence for conducting CPS research. For successful involvement of community pharmacists in CPS research, Swedish pharmacy curricula need to include more communication training and inter-professional collaboration, as well as measures to increase research competence.

Since competing commercial priorities hamper community pharmacists' sustainable research involvement, separate research funding is an important facilitator. For surveys to include all eligible patients, services to be relevant for both practice and patients and to target the patients in most need of support with their medication, research collaboration with healthcare, other professions and across pharmacies is also necessary.

## Future perspectives

It is difficult to discuss if and how community pharmacies will be able to participate in research without considering what community pharmacy represents, today and in the future. In this thesis, the term community pharmacy represents the actual setting: Retail pharmacies, situated outside of hospitals and focusing on dispensing of prescription drugs and sales of OTC drugs and other more or less health related products. Consequently, a community pharmacist is a pharmacist working in a community pharmacy.

With increasing sales of pharmaceutical products over the Internet, either from retail pharmacies expanding their sales channels or from purely web-based pharmacies, customer encounters are gradually changing. Even though web-based questionnaires can replace a questionnaire completed at the pharmacy counter, there are still methodological problems that need to be resolved, e.g. technical problems when managing a web-based questionnaire (164) and declining response rates.

Services based on an initial real-life patient encounter and potential follow-up visits in a pharmacy will have to be re-designed and evaluated in terms of patient outcome. An interesting case for future pharmacy-based research would thus be to compare knowledge and adherence in patients with and without previous real-life meetings with a pharmacist. Results would be relevant, not just for community pharmacies, but also for the pharmacist profession.

With personal experiences from study IV, I believe that it would be fruitful to explore the experiences of pharmacists being both operative CPS providers and pharmacy managers in a highly commercial environment. If they ultimately are the ones who have to balance the conflicting interests of offering services relevant to patients and healthcare, and managing a business with a commercial focus, understanding their motivation and coping strategies possibly adds important dimensions to the feasibility of pharmacy services research, development and implementation.

Existing literature on respondents' perspectives on health survey participation address e.g. reasons for nonparticipation (165), preferences regarding questionnaire design (166) and reactions to incentives (167,168). How patients perceive being surveyed when redeeming their prescriptions in a

community pharmacy has not yet been studied, and is not included in this thesis. Similarly, patients' perceptions regarding implemented pharmaceutical services have been studied (128–130,169–172) but not their perceptions and experiences of participating in services research. To fully understand the feasibility of conducting research in community pharmacies, these perspectives need to be studied.

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## Sammanfattning (summary in Swedish)

Läkemedelsbehandling är en av de vanligaste åtgärderna inom hälso- och sjukvården. Över tid har antalet tillgängliga läkemedel ökat, och de läkemedel som numera introduceras på marknaden är ofta dyra och rekommenderas ofta bara när det finns en bevisad nytta med behandlingen, både kliniskt och hälsoekonomiskt.

Uppföljning av hur läkemedel förskrivs och används har därför blivit allt viktigare, och tillgång till data är en nyckelfaktor. Kunskap om olika datakällor och -insamlingsmetoder behövs för att kunna bedöma värdet av de data som genereras. Sedan 2006 har man på utvalda svenska apotek genomfört enkätundersökningar om kundernas läkemedelsanvändning. De har genomförts i samband med att kunderna hämtat ut receptförskrivna läkemedel. Enstaka studier har visat att metoden inte når ett representativt urval av deltagare. Hur väl öppenvårdsapotek generellt sett lämpar sig för enkätstudier, och apotekspersonalen för att intervjua, har dock varit okänt. Ett av syftena med denna avhandling är att belysa just detta.

Då problemen med felaktig läkemedelsanvändning är kända har farmaceuter börjat övergå från standardiserad rådgivning till rådgivningstjänster anpassade till enskilda läkemedelsanvändare. Tjänsterna tillhandahålls inom sjukvården eller på öppenvårdsapotek, antingen i direkta möten, via telefon eller digitalt. Svenska apotek har sedan 10–15 år tillbaka rekryterat kunder till så kallade patientstödsprogram, som syftar till att öka kundernas kunskap och förbättra långtidspåföljsamheten till läkemedelsbehandlingen. Stödprogrammen har sedan genomförts av så kallade vårdtjänsteföretag. Det finns numera vetenskapliga studier som visar att dessa tjänster kan ha effekt, men resultaten är inte är entydiga, så det är fortsatt viktigt att tjänsterna utvärderas i forskningsstudier. Det behöver även klargöras vilka förutsättningar som krävs för att farmaceuter ska kunna medverka i forskning, vilket är det andra syftet med denna avhandling.

Kunder som erbjudits att svara på en enkät på apotek under 2006-2012 har jämförts avseende ålder och kön med alla svenska patienter som fått samma läkemedel under samma period (artikel 1). Jämförelsen omfattar drygt 15 000 personer, och visar att kunder som var 75 år eller äldre inte erbjudits att delta i enkätstudier på apotek i samma utsträckning som övriga kunder, därför att de mer sällan gått till apoteket och hämtar ut sina läkemedel själva.

Detta gällde för samtliga undersökta läkemedelsgrupper och bidrog till att resultaten i undersökningarna representerade en yngre, sannolikt något friskare, grupp än de genomsnittliga användarna.

Farmaceuternas syn på arbetet med enkäterna undersöktes med en anonym enkät spridd via alla medverkande apotek och enskilda intervjuer med 19 farmaceuter (artikel 2). De var positiva till att genomföra enkätintervjuerna, bl. a för att det bidrar till en bättre kunddialog om läkemedel. Att behöva genomföra enkäterna i anslutning till receptexpedieringen uppfattades dock som ett stressmoment, och det var vanligt att farmaceuterna avstod från enkäterna för att inte öka sin arbetsbörda. Kunder som uppfattades som komplexa och tidskrävande blev därför inte erbjudna att medverka. Resultatet visar att extra resurser behövs för att enkäterna ska genomföras utan att enkätstudiernas kvalitet påverkas.

Enkäter riktade till kunder som köper receptfria läkemedel användes som metod i en studie av användningen av triptaner (migränläkemedel) i Stockholm (artikel 3). Användningen av receptbelagda triptaner studerades med hjälp av registerdata. Resultatet visar att förskrivningen av triptaner skett på ett säkert sätt, men med bristande dokumentation av förskrivningsorsak eller med förskrivning vid annan sjukdom än migrän. Patienter som köpte receptfria triptaner hade oftast fått sin migrändiagnos av en läkare och hade använt receptbelagda triptaner tidigare. Båda patientgrupper hade en mycket låg användning av förebyggande migränläkemedel. Resultatet visade även på stora metodmässiga utmaningar vid rekrytering av deltagare i enkäten och beräkning av svarsfrekvens, dvs faktorer som påverkar studiens kvalitet.

Ett pågående patientstödsprogram som riktar sig till patienter som hämtar ut blodfettsänkande läkemedel på öppenvårdsapotek utvärderas i ett forskningsprojekt. Farmaceuternas syn på att medverka i forskning undersöktes i gruppintervjuer som visade att det fanns en generell förståelse för att forskning är viktig för att utveckla apoteksverksamheten och farmaceuternas yrkesroll, men att man upplevde en rad påtagliga hinder. Ett fokus på försäljning av produkter och konkurrens mellan apoteksföretag försvårar både forskning om och implementering av farmaceutiska tjänster på öppenvårdsapotek. För att bidra i forskning behöver farmaceuterna bättre kommunikations- och forskningsträning, och ett ökat samarbete mellan olika apotekföretag respektive apotek och hälso- och sjukvård behöver utvecklas.

I avhandlingen undersöks inte patienters syn på att svara på enkäter eller medverka i annan forskning kopplad till apotek, något som förstås är relevant i sammanhanget. Likaså saknas andra aktörers syn på värdet av apoteksbaserade enkäter eller annan forskning. För att fullt ut förstå hur väl forskning på apotek kan fungera behöver även dessa perspektiv studeras.

Sammanfattningsvis visar avhandlingen att svenska apotek med sin stora kontaktyta mot patienter både kan bidra med enkätstudier kring läkemedelsanvändning och medverka i forskning kring farmaceutiska tjänster, men med faktiska begränsningar och upplevda hinder. Automatiskt når man ett urval av något yngre kunder, då de äldsta inte går till apoteket i samma utsträckning som övriga, och vissa mer tidskrävande kunder utesluts aktivt. Det gör att enkäter och förfrågningar om att delta i forskning inte når de största läkemedelsanvändarna, och därför inte blir representativa. Öppenvårdsapotekens kommersiella fokus upplevs försvåra medverkan i forskning, som inte prioriteras. Ytterligare resurser, kommunikationsträning och ökad forskningskunskap identifieras som avgörande förbättringsfaktorer, tillsammans med ett utökat samarbete med hälso- och sjukvård och alla apoteksföretag.

# References

1. Hepler CD, Strand LM. Opportunities and responsibilities in pharmaceutical care. *Am J Hosp Pharm* 1990;47(3):533–43.
2. J. W. Foppe van Mil, Schulz M. A review of pharmaceutical care in community pharmacy in Europe. *Harv Health Policy Rev.* 7/2006(1):155–68.
3. Bond C. The need for pharmacy practice research. *Int J Pharm Pract* 2006;14(1):1–2.
4. Koster ES, Blom L, Philbert D et al. The Utrecht Pharmacy Practice network for Education and Research: a network of community and hospital pharmacies in the Netherlands. *Int J Clin Pharm* 2014;36(4):669–74.
5. Perraudin C, Bugnon O, Pelletier-Fleury N. Expanding professional pharmacy services in European community setting: Is it cost-effective? A systematic review for health policy considerations. *Health Policy Amst Neth* 2016;120(12):1350–62.
6. Elsevier M (ed). *Drug utilization research: methods and applications*. 2016: John Wiley & Sons Inc.
7. Mousnad MA, Shafie AA, Ibrahim MI. Systematic review of factors affecting pharmaceutical expenditures. *Health Policy Amst Neth.* 2014;116(2–3):137–46.
8. Rothman KJ. *Epidemiology: an introduction* (2<sup>nd</sup> ed). 2012: New York, NY: Oxford University Press.
9. Eichler H-G, Abadie E, Breckenridge A et al. Bridging the efficacy-effectiveness gap: a regulator’s perspective on addressing variability of drug response. *Nat Rev Drug Discov.* 2011;10(7):495–506.
10. Lu CY. Observational studies: a review of study designs, challenges and strategies to reduce confounding. *Int J Clin Pract* 2009;63(5):691–7.
11. Wettermark B. The intriguing future of pharmacoepidemiology. *Eur J Clin Pharmacol* 2013;69 Suppl 1:43–51.
12. Wettermark B, Hammar N, Fored CM et al. The new Swedish Prescribed Drug Register--opportunities for pharmacoepidemiological research and experience from the first six months. *Pharmacoepidemiol Drug Saf* 2007;16(7):726–35.
13. Heerdink ER, Leufkens HG, Koppedraaijer C et al. Information on drug use in the elderly: a comparison of pharmacy, general-practitioner and patient data. *Pharm World Sci* 1995;17(1):20–4.
14. Orrico KB. Sources and types of discrepancies between electronic medical records and actual outpatient medication use. *J Manag Care Pharm* 2008;14(7):626–31.
15. Ekedahl A, Brosius H, Jönsson J et al. Discrepancies between the electronic medical record, the prescriptions in the Swedish national prescription repository and the current medication reported by patients. *Pharmacoepidemiol Drug Saf* 2011;20(11):1177–83.

16. Hayward KL, Valery PC, Cottrell WN et al. Prevalence of medication discrepancies in patients with cirrhosis: a pilot study. *BMC Gastroenterol* 2016;16:114.
17. Coorevits P, Sundgren M, Klein GO et al. Electronic health records: new opportunities for clinical research. *J Intern Med* 2013;274(6):547–60.
18. Murray MD. Use of Data from Electronic Health Records for Pharmacoepidemiology. *Curr Epidemiol Rep* 2014;1(4):186–93.
19. Larsen MD, Cars T, Hallas J. A MiniReview of the use of hospital-based databases in observational inpatient studies of drugs. *Basic Clin Pharmacol Toxicol* 2013;112(1):13–8.
20. Emilsson L, Lindahl B, Köster M et al. Review of 103 Swedish Healthcare Quality Registries. *J Intern Med* 2015;277(1):94–136.
21. Hartzema AG, Tilson HH, Chan KA (eds). *Pharmacoepidemiology and therapeutic risk management* (1<sup>st</sup> ed). 2008: Cincinnati, OH: Harvey Whitney Books.
22. Haukka J, Suvisaari J, Tuulio-Henriksson A et al. High concordance between self-reported medication and official prescription database information. *Eur J Clin Pharmacol* 2007;63(11):1069–74.
23. Lau HS, de Boer A, Beuning KS et al. Validation of pharmacy records in drug exposure assessment. *J Clin Epidemiol* 1997;50(5):619–25.
24. Monster TBM, Janssen WMT, de Jong PE, de Jong-van den Berg LTW, PREVEND Study Group. Prevention of RENal and Vascular ENT Stage Disease. Pharmacy data in epidemiological studies: an easy to obtain and reliable tool. *Pharmacoepidemiol Drug Saf* 2002;11(5):379–84.
25. Dahlén E, Almqvist C, Bergström A et al. Factors associated with concordance between parental-reported use and dispensed asthma drugs in adolescents: findings from the BAMSE birth cohort. *Pharmacoepidemiol Drug Saf* 2014;23(9):942–9.
26. Robson C. *Real world research: a resource for users of social research methods in applied settings* (3<sup>rd</sup> ed). 2011: Chichester: Wiley.
27. Strandell B, Norgren-Holst E, Tran N et al. OTC use of a topical nasal spray solution containing xylometazoline plus ipratropium in patients with common cold. *Int J Clin Pharmacol Ther* 2009;47(12):744–51.
28. Carvajal A, Sáinz M, Velasco V et al. Emergency contraceptive pill safety profile. Comparison of the results of a follow-up study to those coming from spontaneous reporting. *Pharmacoepidemiol Drug Saf* 2015;24(1):93–7.
29. Motola G, Russo F, Mazzeo F, Rinaldi B et al. Over-the-counter oral non-steroidal anti-inflammatory drugs: a pharmacoepidemiologic study in southern Italy. *Adv Ther* 2001;18(5):216–22.
30. Sinclair HK, Bond CM, Hannaford PC. Long term follow-up studies of users of nonprescription medicines purchased from community pharmacies: some methodological issues. *Drug Saf* 2001;24(12):929–38.
31. Brusa P, Allais G, Bussone G et al. Migraine attacks in the pharmacy: a survey in Piedmont, Italy. *Neurol Sci Off J Ital Neurol Soc Ital Soc Clin Neurophysiol* 2014;35 Suppl 1:5–9.
32. Mehuys E, Paemeleire K, Van Hees T et al. Self-medication of regular headache: a community pharmacy-based survey. *Eur J Neurol* 2012;19(8):1093–9.
33. Carvajal A, Arias LHM, Vega E et al. Gastroprotection during the administration of non-steroidal anti-inflammatory drugs. A drug-utilization study. *Eur J Clin Pharmacol* 2004;60(6):439–44.

34. Söderberg KG, Frisk P, Nilsson JLG. [Inappropriate drugs for the elderly are mainly prescribed within primary health care. Recommendation on drugs that "should be avoided" is not known well enough]. *Läkartidningen* 2012;109(20–21):1019–21.
35. Silvennoinen R, Turunen JH, Kovanen PT et al. Attitudes and actions: A survey to assess statin use among Finnish patients with increased risk for cardiovascular events. *J Clin Lipidol* 2017;11(2):485–94.
36. Frisk P, Mellgren T-O, Hedberg N et al. Utilisation of angiotensin receptor blockers in Sweden: combining survey and register data to study adherence to prescribing guidelines. *Eur J Clin Pharmacol* 2008;64(12):1223–9.
37. Göbel H, Gessner U, Petersen-Braun M et al. [Acetylsalicylic acid in self-medication of migraine. A pharmacy-based observational study]. *Schmerz Berl Ger* 2007;21(1):49–54, 56.
38. Wouters H, Van Dijk L, Geers HCJ, Winters NA et al. Understanding Statin Non-Adherence: Knowing Which Perceptions and Experiences Matter to Different Patients. *PloS One*. 2016;11(1):e0146272.
39. Holsappel IGA, Koster ES, Winters NA et al. Prescribing with indication: uptake of regulations in current practice and patients opinions in the Netherlands. *Int J Clin Pharm* 2014;36(2):282–6.
40. Kanavos, P, Schurer, W, Vogler, S. The pharmaceutical distribution chain in the European Union: structure and impact on pharmaceutical prices. European Commission, Brussels, Belgium; 2011 [accessed 2018-01-10]. Available at: <http://eprints.lse.ac.uk/51051/>
41. WHO. Health systems financing: the path to universal coverage. 2010: Geneva (The world health report).
42. Seston E, Hassell K, Cantrill J et al. Experiences of establishing and maintaining a community pharmacy research network. *Prim Health Care Res Dev* 2003;4(3):245–55.
43. Patel P, Hemmeger H, Kozak MA et al. Community pharmacist participation in a practice-based research network: a report from the Medication Safety Research Network of Indiana (Rx-SafeNet). *J Am Pharm Assoc JAPhA* 2015;55(6):649–55.
44. Tolonen H, Ahonen S, Jentoft S, et al, European Health Examination Pilot Project. Differences in participation rates and lessons learned about recruitment of participants--the European Health Examination Survey Pilot Project. *Scand J Public Health* 2015;43(2):212–9.
45. SFS 1996:1157 Act concerning drug and therapeutics committees. Available at: [https://www.riksdagen.se/sv/dokument-lagar/dokument/svenskforfattningssamling/lag-19961157-om-lakemedelskommitteer\\_sfs-1996-1157](https://www.riksdagen.se/sv/dokument-lagar/dokument/svenskforfattningssamling/lag-19961157-om-lakemedelskommitteer_sfs-1996-1157).
46. Wettermark B, Godman B, Andersson K et al. Recent national and regional drug reforms in Sweden: implications for pharmaceutical companies in Europe. *PharmacoEconomics* 2008;26(7):537–50.
47. TLV. Patient co-payment scheme for prescription drugs. Available at: <http://www.tlv.se/In-English/medicines-new/the-swedish-high-cost-threshold/how-it-works/>
48. SFS 2002:160 Act on Pharmaceutical Benefits. Available at: [https://www.riksdagen.se/sv/dokument-lagar/dokument/svenskforfattningssamling/lag-2002160-om-lakemedelsformaner-mm\\_sfs-2002-160](https://www.riksdagen.se/sv/dokument-lagar/dokument/svenskforfattningssamling/lag-2002160-om-lakemedelsformaner-mm_sfs-2002-160).
49. Kieler H, Ekblom A, Fored M et al. [Follow up studies as a condition for drug subsidizing]. *Läkartidningen* 2009;106(20):1406–7.

50. Wallerstedt SM, Wettermark B, Hoffmann M. The First Decade with the Swedish Prescribed Drug Register - A Systematic Review of the Output in the Scientific Literature. *Basic Clin Pharmacol Toxicol* 2016;119(5):464–9.
51. Wisell K, Winblad U, Sporrang SK. Reregulation of the Swedish pharmacy sector-A qualitative content analysis of the political rationale. *Health Policy Amst Neth* 2015;119(5):648–53.
52. Swedish Pharmacy Association. Retail Pharmacy Report 2017. Available at: <http://www.sverigesapoteksforening.se/wp-content/uploads/Branschrappport2017.pdf>
53. Frisk P, Bergman U, Källemark-Sporrang S. Exploring community pharmacists' experiences of surveying patients for drug utilization research purposes. *Int J Clin Pharm* 2015;37(3):522–8.
54. Frisk P, Rydberg T, Carlsten A, Ekedahl A. Patients' experiences with generic substitution: a Swedish pharmacy survey. *J Pharm Health Serv Res* 2011;2(1):9–15.
55. SFS 2003:460 Act concerning the Ethical Review of Research Involving Humans. Available at: <https://www.epn.se/en/start/regulations/>
56. European Society of Opinion and Market Research. ICC/ESOMAR International Code on Market, Opinion and Social Research and Data Analytics. [accessed 2017-11-30]. Available at: <https://www.esomar.org/what-we-do/code-guidelines>
57. Campbell MJ, Walters SJ, Machin D. Medical statistics: a textbook for the health sciences (4<sup>th</sup> ed). 2007: Chichester, England; Hoboken, NJ: Wiley.
58. Gerhard T. Bias: considerations for research practice. *Am J Health-Syst Pharm AJHP Off J Am Soc Health-Syst Pharm* 2008;65(22):2159–68.
59. Schwartz S, Campbell UB, Gatto NM et al. Toward a clarification of the taxonomy of "bias" in epidemiology textbooks. *Epidemiol Camb Mass* 2015;26(2):216–22.
60. Haneuse S. Distinguishing Selection Bias and Confounding Bias in Comparative Effectiveness Research. *Med Care* 2016;54(4):e23-9.
61. Ax F, Ekedahl A. Electronically transmitted prescriptions not picked up at pharmacies in Sweden. *Res Soc Adm Pharm* 2010;6(1):70–7.
62. Fischer MA, Choudhry NK, Brill G et al. Trouble getting started: predictors of primary medication nonadherence. *Am J Med* 2011;124(11):1081.e9-22.
63. Tamblyn R, Eguale T, Huang A et al. The incidence and determinants of primary nonadherence with prescribed medication in primary care: a cohort study. *Ann Intern Med* 2014;160(7):441–50.
64. Gadkari AS, McHorney CA. Medication nonfulfillment rates and reasons: narrative systematic review. *Curr Med Res Opin* 2010;26(3):683–705.
65. Frisk P, Källemark-Sporrang S, Wettermark B. Selection bias in pharmacy-based patient surveys. *Pharmacoepidemiol Drug Saf* 2014;23(2):128–39.
66. Groves RM, Peytcheva E. The Impact of Nonresponse Rates on Nonresponse Bias A Meta-Analysis. *Public Opin Q* 2008;72(2):167–89.
67. Sogaard AJ, Selmer R, Bjertness E et al. The Oslo Health Study: The impact of self-selection in a large, population-based survey. *Int J Equity Health* 2004;3(1):3.
68. Tolonen H, Helakorpi S, Talala K et al. 25-year trends and socio-demographic differences in response rates: Finnish adult health behaviour survey. *Eur J Epidemiol*. 2006;21(6):409–15.
69. Nummela O, Sulander T, Helakorpi S et al. Register-based data indicated nonparticipation bias in a health study among aging people. *J Clin Epidemiol* 2011;64(12):1418–25.

70. Elnegaard S, Andersen RS, Pedersen AF et al. Self-reported symptoms and healthcare seeking in the general population--exploring "The Symptom Iceberg". *BMC Public Health*. 2015;15:685.
71. Ganguli M, Lytle ME, Reynolds MD et al. Random versus volunteer selection for a community-based study. *J Gerontol A Biol Sci Med Sci* 1998;53(1):M39-46.
72. Knudsen AK, Hotopf M, Skogen JC et al. The health status of nonparticipants in a population-based health study: the Hordaland Health Study. *Am J Epidemiol* 2010;172(11):1306-14.
73. Bradburn NM, Sudman S, Wansink B. Asking questions: the definitive guide to questionnaire design-- for market research, political polls, and social and health questionnaires. Revised edition. 2004: San Francisco, CA: Jossey-Bass.
74. Løkkegaard EL, Johnsen SP, Heitmann BL et al. The validity of self-reported use of hormone replacement therapy among Danish nurses. *Acta Obstet Gynecol Scand* 2004;83(5):476-81.
75. Boudreau DM, Daling JR, Malone KE et al. A validation study of patient interview data and pharmacy records for antihypertensive, statin, and antidepressant medication use among older women. *Am J Epidemiol* 2004;159(3):308-17.
76. Klungel OH, de Boer A, Paes AH et al. Agreement between self-reported antihypertensive drug use and pharmacy records in a population-based study in The Netherlands. *Pharm World Sci* 1999;21(5):217-20.
77. Nielsen MW, Søndergaard B, Kjølner M et al. Agreement between self-reported data on medicine use and prescription records vary according to method of analysis and therapeutic group. *J Clin Epidemiol* 2008;61(9):919-24.
78. Cipolle RJ, Strand LM, Morley PC. *Pharmaceutical care practice: the clinician's guide* (2<sup>nd</sup> ed). 2004: New York: McGraw-Hill, Medical Pub. Division.
79. Allemann SS, van Mil JWF, Botermann L et al. Pharmaceutical care: the PCNE definition 2013. *Int J Clin Pharm* 2014;36(3):544-55.
80. Blackburn DF, Yakiwchuk EM, Jorgenson DJ et al. Proposing a redefinition of pharmaceutical care. *Ann Pharmacother* 2012;46(3):447-9.
81. Roberts AS, Benrimoj S (Charlie), Chen TF et al. Implementing cognitive services in community pharmacy: a review of facilitators used in practice change. *Int J Pharm Pract* 2006;14(3):163-70.
82. Benrimoj C, Feletto E, Gastelurrutia M et al. A holistic and integrated approach to implementing cognitive pharmaceutical services. *ARS Pharm*. 2010(51):69-87.
83. Bonanno Sarah Thum. From making medicines to optimising outcomes: The evolution of a profession 1912-2012. *Federation Internationale Pharmaceutique*, 2012.
84. World Health Organisation. *Role of the pharmacist in the healthcare system*. WHO; 1994.
85. Mossialos E, Courtin E, Naci H et al. From "retailers" to health care providers: Transforming the role of community pharmacists in chronic disease management. *Health Policy Amst Neth* 2015;119(5):628-39.
86. Martins SF, van Mil JWF, da Costa FA. The organizational framework of community pharmacies in Europe. *Int J Clin Pharm* 2015;37(5):896-905.
87. Hughes CM, Hawwa AF, Scullin C et al. Provision of pharmaceutical care by community pharmacists: a comparison across Europe. *Pharm World Sci* 2010;32(4):472-87.

88. Christensen DB, Farris KB. Pharmaceutical care in community pharmacies: practice and research in the US. *Ann Pharmacother* 2006;40(7–8):1400–6.
89. Farris KB, Fernandez-Llimos F, Benrimoj SIC. Pharmaceutical care in community pharmacies: practice and research from around the world. *Ann Pharmacother* 2005;39(9):1539–41.
90. Mossialos E, Naci H, Courtin E. Expanding the role of community pharmacists: policymaking in the absence of policy-relevant evidence? *Health Policy Amst Neth* 2013;111(2):135–48.
91. Elliott RA, Boyd MJ, Salema N-E et al. Supporting adherence for people starting a new medication for a long-term condition through community pharmacies: a pragmatic randomised controlled trial of the New Medicine Service. *BMJ Qual Saf* 2016;25(10):747–58.
92. Costa S, Santos C, Silveira J. Community pharmacy services in Portugal. *Ann Pharmacother* 2006;40(12):2228–34.
93. Kaae S, Søndergaard B, Haugbølle LS et al. Sustaining delivery of the first publicly reimbursed cognitive service in Denmark: a cross-case analysis. *Int J Pharm Pract* 2010;18(1):21–7.
94. Manfrin A, Tinelli M, Thomas T et al. A cluster randomised control trial to evaluate the effectiveness and cost-effectiveness of the Italian medicines use review (I-MUR) for asthma patients. *BMC Health Serv Res* 2017;17(1):300.
95. Pammatt R, Jorgenson D. Eligibility requirements for community pharmacy medication review services in Canada. *Can Pharm J CPJ Rev Pharm Can RPC* 2014;147(1):20–4.
96. Armour CL, Reddel HK, LeMay KS et al. Feasibility and effectiveness of an evidence-based asthma service in Australian community pharmacies: a pragmatic cluster randomized trial. *J Asthma Off J Assoc Care Asthma* 2013;50(3):302–9.
97. Craig P, Dieppe P, Macintyre S et al. Developing and evaluating complex interventions: the new Medical Research Council guidance. *Int J Nurs Stud* 2013;50(5):587–92.
98. Moullin JC, Sabater-Hernández D, Benrimoj SI. Model for the evaluation of implementation programs and professional pharmacy services. *Res Soc Adm Pharm* 2016;12(3):515–22.
99. Awaisu A, Alsalimy N. Pharmacists' involvement in and attitudes toward pharmacy practice research: A systematic review of the literature. *Res Soc Adm Pharm* 2015;11(6):725–48.
100. Cvijovic K, Boon H, Jaeger W et al. Pharmacists' participation in research: a case of trying to find the time. *Int J Pharm Pract* 2010;18(6):377–83.
101. Saini B, Brilliant M, Filipovska J et al. Factors influencing Australian community pharmacists' willingness to participate in research projects - an exploratory study. *Int J Pharm Pract* 2006;14(3):179–88.
102. Armour C, Brilliant M, Krass I. Pharmacists' views on involvement in pharmacy practice research: Strategies for facilitating participation. *Pharm Pract* 2007;5(2):59–66.
103. Ellerby DA, Williams, A, Winfield AJ. The level of interest in pharmacy practice research among community pharmacists. *Pharm J*. 1993(251):321–2.
104. Liddell H. Attitudes of community pharmacists regarding involvement in practice research. *Pharm J*. 1996(256):905–7.
105. Abdel Shaheed C, Maher CG, Williams KA et al. Participation of pharmacists in clinical trial recruitment for low back pain. *Int J Clin Pharm* 2014;36(5):986–94.

106. Simpson SH, Johnson JA, Biggs C et al. Practice-based research: lessons from community pharmacist participants. *Pharmacotherapy* 2001;21(6):731–9.
107. Krska J, Kennedy EF, Hansford D et al. Pharmacists' opinion on their involvement in a community pharmacy based practice research study. *Pharm J* 1998(261):b54.
108. Kozak MA, Gernant SA, Hemmeger HM et al. Lessons learned in the growth and maturation stages of a community pharmacy practice-based research network: Experiences of the Medication Safety Research Network of Indiana (Rx-SafeNet). *Innov Pharm* 2015;6(2). pii: Article 203.
109. Rosenbloom K, Taylor K, Harding G. Community pharmacists' attitudes towards research. *Int J Pharm Pract* 2000;8(2):103–10.
110. Peterson GM, Jackson SL, Fitzmaurice KD et al. Attitudes of Australian pharmacists towards practice-based research. *J Clin Pharm Ther* 2009;34(4):397–405.
111. Hebert J, Laliberte M-C, Berbiche D et al. The willingness of community pharmacists to participate in a practice-based research network. *Can Pharm J Rev Pharm Can* 2013;146(1):47–54.
112. Koshy S. Pharmacy practice-based research networks: do pharmacists need them? *Int J Pharm Pract* 2014;22(6):433–6.
113. Snyder ME, Frail CK, Seel LV et al. Experience Developing a Community Pharmacy Practice-based Research Network. *Innov Pharm.* 2012;3(2). pii: Article 78
114. Goode J-VKR, Mott DA, Chater R. Collaborations to facilitate success of community pharmacy practice-based research networks. *J Am Pharm Assoc JAPhA* 2008;48(2):153–62.
115. Sinclair H, Bond C, Largue G et al. Community pharmacy provision of allergic rhinitis treatments: a longitudinal study of patient reported outcome. *Int J Pharm Pract* 2005;13(4):249–56.
116. Manfrin A, Thomas T, Krska J. Randomised evaluation of the Italian medicines use review provided by community pharmacists using asthma as a model (RE I-MUR). *BMC Health Serv Res* 2015;15:171.
117. Blackburn DF, Evans CD, Eurich DT et al. Community Pharmacists Assisting in Total Cardiovascular Health (CPATCH): A Cluster-Randomized, Controlled Trial Testing a Focused Adherence Strategy Involving Community Pharmacies. *Pharmacotherapy* 2016;36(10):1055–64.
118. Latif A, Boardman H. Community pharmacists' attitudes towards medicines use reviews and factors affecting the numbers performed. *Pharm World Sci* 2008;30(5):536–43.
119. Lisper B, Nilsson JL. The asthma year in Swedish pharmacies: a nationwide information and pharmaceutical care program for patients with asthma. *Ann Pharmacother* 1996;30(5):455–60.
120. Ax F, Brånstad J-O, Westerlund T. Pharmacy counselling models: a means to improve drug use. *J Clin Pharm Ther* 2010;35(4):439–51.
121. Westerlund T, Marklund B. Assessment of the clinical and economic outcomes of pharmacy interventions in drug-related problems. *J Clin Pharm Ther* 2009;34(3):319–27.
122. Westerlund LT, Björk HT. Pharmaceutical Care in Community Pharmacies: Practice and Research in Sweden. *Ann Pharmacother* 2006;40(6):1162–9.
123. Nordén-Hägg A, Källemark-Sporrong S, Lindblad ÅK. Exploring the relationship between safety culture and reported dispensing errors in a large sample of Swedish community pharmacies. *BMC Pharmacol Toxicol* 2012;13:4.

124. Montgomery AT, Källemark Sporrang S, Manap N et al. Receiving a pharmaceutical care service compared to receiving standard pharmacy service in Sweden--How do patients differ with regard to perceptions of medicine use and the pharmacy encounter? *Res Soc Adm Pharm* 2010;6(3):185–95.
125. Olsson E, Ingman P, Ahmed B et al. Pharmacist-patient communication in Swedish community pharmacies. *Res Soc Adm Pharm* 2014;10(1):149–55.
126. Renberg T, Wichman Törnqvist K et al. Pharmacy users' expectations of pharmacy encounters: a Q-methodological study. *Health Expect Int J Public Particip Health Care Health Policy* 2011;14(4):361–73.
127. Montgomery A. Counselling in Swedish community pharmacies Understanding the process of pharmaceutical care service. 2009 [Accessed 2016-08-03]. Available at: <http://www.diva-portal.org/smash/get/diva2:241937/FULLTEXT01.pdf>
128. Montgomery AT, Sporrang SK, Tully MP et al. Follow-up of patients receiving a pharmaceutical care service in Sweden. *J Clin Pharm Ther* 2008;33(6):653–62.
129. Latif A, Boardman HF, Pollock K. Understanding the patient perspective of the English community pharmacy Medicines Use Review (MUR). *Res Soc Adm Pharm* 2013;9(6):949–57.
130. Renberg T, Lindblad AK, Tully MP. Exploring subjective outcomes perceived by patients receiving a pharmaceutical care service. *Res Soc Adm Pharm* 2006;2(2):212–31.
131. Medical Products Agency. Att genomföra strukturerade läkemedelssamtal på svenska apotek - slutrapport. 2014. Available at: <https://lakemedelsverket.se/overgripande/Om-Lakemedelsverket/NLS-holder/Statusrapportering-NLS>
132. Kvalitet och säkerhet på apoteksmarknaden: delbetänkande. Stockholm: Wolters Kluwer; 2017 [accessed 2017-04.20]. Available at: <http://www.regeringen.se/rattsdokument/statens-offentliga-utredningar/2017/03/sou-201715>
133. Berglind IA, Kieler H, Linder M et al. Värdet av statiner — användningsmönster och följsamhet vid behandling. SNS; [accessed 2015-12-16]. Available at: <http://www.sns.se/aktuellt/fem-rapporter-om-vardet-av-nya-lakemedel/>
134. Kooij MJ, Heerdink ER, van Dijk L et al. Effects of Telephone Counseling Intervention by Pharmacists (TelCIP) on Medication Adherence; Results of a Cluster Randomized Trial. *Front Pharmacol* 2016;7:269.
135. WHO. Guidelines for ATC classification and DDD assignment 2013. 2012: WHO Collaborating Centre for Drug Statistics Methodology, Oslo. Available at: <http://www.whocc.no>.
136. Altman DG (ed). *Statistics with confidence: confidence intervals and statistical guidelines* (2<sup>nd</sup> ed). 2011: London: BMJ Books.
137. Ivankova NV, Creswell JW, Stick SL. Using Mixed-Methods Sequential Explanatory Design: From Theory to Practice. *Field Methods* 2006;18(1):3–20.
138. Sandelowski M. Whatever happened to qualitative description? *Res Nurs Health* 2000;23(4):334–40.
139. Sandelowski M. What's in a name? Qualitative description revisited. *Res Nurs Health* 2010;33(1):77–84.
140. von Euler M, Keshani S, Baatz K et al. Utilization of triptans in Sweden; analyses of over the counter and prescription sales. *Pharmacoepidemiol Drug Saf* 2014;23(12):1288–93.

141. Carlsson AC, Wändell P, Ösby U et al. High prevalence of diagnosis of diabetes, depression, anxiety, hypertension, asthma and COPD in the total population of Stockholm, Sweden - a challenge for public health. *BMC Public Health* 2013;13:670.
142. Krueger RA, Casey MA. *Focus groups: a practical guide for applied research* (4<sup>th</sup> ed). 2009: Los Angeles: SAGE.
143. Hsieh H-F, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res* 2005;15(9):1277–88.
144. Hill CE, Thompson BJ, Williams EN. *A Guide to Conducting Consensual Qualitative Research*. *Couns Psychol* 1997;25(4):517–72.
145. SFS 1998:204 The Personal Data Act. The Swedish Data Protection Authority; [accessed 2017-11-15]. Available at: <http://www.datainspektionen.se/in-english/legislation/the-personal-data-act/>
146. Loder E, Burch R, Rizzoli P. The 2012 AHS/AAN guidelines for prevention of episodic migraine: a summary and comparison with other recent clinical practice guidelines. *Headache* 2012;52(6):930–45.
147. Da Cas R, Nigro A, Terrazzino S et al. Triptan use in Italy: Insights from administrative databases. *Cephalalgia Int J Headache* 2015;35(7):619–26.
148. Johnson H, Guhl G, Arora J et al. Migraine in students of a US medical school. *Fam Med* 2014;46(8):615–9.
149. Dekker F, Dieleman JP, Neven AK et al. Preventive treatment for migraine in primary care, a population-based study in the Netherlands. *Cephalalgia Int J Headache* 2013;33(14):1170–8.
150. Sudman S, Bradburn NM, Schwarz N. *Thinking about answers: the application of cognitive processes to survey methodology* (1<sup>st</sup> ed). 1996: San Francisco: Jossey-Bass Publishers.
151. Li M, Harris I, Lu ZK. Differences in proxy-reported and patient-reported outcomes: assessing health and functional status among medicare beneficiaries. *BMC Med Res Methodol* 2015;15:62.
152. Devine A, Taylor SJC, Spencer A et al. The agreement between proxy and self-completed EQ-5D for care home residents was better for index scores than individual domains. *J Clin Epidemiol* 2014;67(9):1035–43.
153. Ekholm O, Hesse U, Davidsen M et al. The study design and characteristics of the Danish national health interview surveys. *Scand J Public Health* 2009;37(7):758–65.
154. De Vera MA, Campbell NKJ, Chhina H et al. Practical strategies and perceptions from community pharmacists following their experiences with conducting pharmacy practice research: a qualitative content analysis. *Int J Pharm Pract* 2017. doi: 10.1111/ijpp.12409. [Epub ahead of print]
155. Bhagavathula AS, Gebreyohannes EA, Gebresillassie BM et al. Community pharmacists' interest in and attitude to pharmacy practice research in Ethiopia: A cross-sectional study. *PloS One*. 2017;12(6):e0178919.
156. Fakeye TO, Adisa R, Olukotun RT et al. Hospital and community pharmacists' perception of the scope, barriers and challenges of pharmacy practice-based research in Nigeria. *Pharm Pract* 2017;15(1):881.
157. Furu K, Wettermark B, Andersen M et al. The Nordic countries as a cohort for pharmacoepidemiological research. *Basic Clin Pharmacol Toxicol* 2010;106(2):86–94.
158. Svensberg K, Källemark Sporrang S, Håkonsen H et al. "Because of the circumstances, we cannot develop our role": Norwegian community pharmacists' perceived responsibility in role development. *Int J Pharm Pract* 2014. doi: 10.1111/ijpp.12154. [Epub ahead of print]

159. Marshall C, Rossman GB. Designing qualitative research (4<sup>th</sup> ed). 2006: Thousand Oaks, Calif: Sage Publications.
160. Noyce PR. Providing patient care through community pharmacies in the UK: policy, practice, and research. *Ann Pharmacother* 2007;41(5):861–8.
161. Roberts AS, Benrimoj SI, Chen TF et al. Practice change in community pharmacy: quantification of facilitators. *Ann Pharmacother* 2008;42(6):861–8.
162. SCB. Population statistics from Statistics Sweden. [Accessed 2017-12-29]. Available at: <http://www.scb.se>.
163. E-health Agency. Information from the Swedish eHealth Agency. [Accessed 2017-12-29]. Available at: <http://www.ehalsomyndigheten.se>
164. van Gelder MMHJ, Bretveld RW, Roeleveld N. Web-based questionnaires: the future in epidemiology? *Am J Epidemiol* 2010;172(11):1292-8.
165. Ahlmark N, Algren MH, Holmberg T et al. Survey nonresponse among ethnic minorities in a national health survey--a mixed-method study of participation, barriers, and potentials. *Ethn Health*. 2015;20(6):611–32.
166. Wenemark M, Persson A, Noorlind Brage H et al. Applying motivation theory to achieve increased respondent satisfaction, response rate and data quality in a self-administered survey. *J Off Stat Internet* 2011;27(2):393–414.
167. Wenemark M, Vernby A, Norberg AL. Can incentives undermine intrinsic motivation to participate in epidemiologic surveys? *Eur J Epidemiol*. april 2010;25(4):231–5.
168. Olsen F, Abelsen B, Olsen J. Improving response rate and quality of survey data with a scratch lottery ticket incentive. *BMC Med Res Methodol* 2012;12(1):52.
169. Kaae S, Sporrang SK. Patients' reasons for accepting a free community pharmacy asthma service. *Int J Clin Pharm* 2015;37(5):917–24.
170. Kooy MJ, Van Geffen ECG, Heerdink ER et al. Patients' general satisfaction with telephone counseling by pharmacists and effects on satisfaction with information and beliefs about medicines: Results from a cluster randomized trial. *Patient Educ Couns* 2015;98(6):797–804.
171. Tinelli M, Bond C, Blenkinsopp A et al. Patient evaluation of a community pharmacy medications management service. *Ann Pharmacother* 2007;41(12):1962–70.
172. Hossain LN, Fernandez-Llimos F, Lockett T et al. Qualitative meta-synthesis of barriers and facilitators that influence the implementation of community pharmacy services: perspectives of patients, nurses and general medical practitioners. *BMJ Open* 2017;7(9):e015471.

# Appendices

## Appendix I

Interview guide individual interviews (paper II)

Age (years)

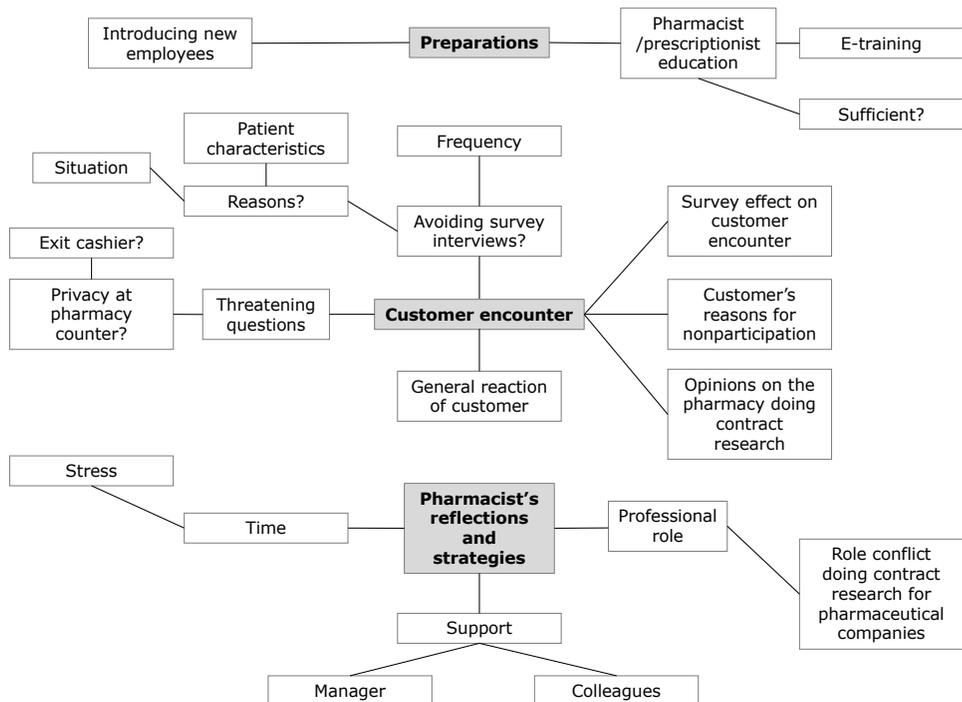
Gender (M/F)

Education (pharmacist/prescriptionist)

No. of years of practice

Experience of pharmacy-based patient surveys (years)

Frequency of survey involvement



## Appendix II

Questionnaire OTC triptans (paper III) *Author's translation*  
*SC=single choice, MC=multiple choice*

**Uppsala university, Karolinska institutet and Stockholm County Council** are investigating how patients use of a certain type of over-the-counter medication intended for the treatment of migraine, so called triptans. Brand names include Zomig Nasal, Zomig Rapimelt, Oripitan and Sumatriptan. The purpose is to establish how these drugs are used, e.g. how often the drug is being used and if patients use both prescription and over-the-counter triptans. Participation is voluntary. No personal identifiers, such as name or birth dates, will be saved and used in the data analysis and presentation. The study is approved by the Ethical Review Board in Stockholm.

1. Do you want to participate? (SC)
  - a. Yes
  - b. No *→exit*
  
2. Is this drug intended for you or somebody else? (SC)
  - a. For me
  - b. For somebody else *→exit*
  
3. What type of headache do you intend to treat with the medication you're buying today? (SC)
  - a. Migraine
  - b. Headache
  - c. Both migraine and headache
  - d. I don't know
  
4. Have you been diagnosed with migraine? (SC)
  - a. Yes *→Question 5*
  - b. No *→Question 6*
  
5. Who gave you the diagnose? (SC)
  - a. A physician
  - b. Another health professional
  - c. A pharmacy staff member
  - d. A relative
  - e. A friend
  - f. Myself

6. Have you ever had a prescription for this type of drug? (SC)  
 If Yes, the drugs may have been named Imigran, Sumatriptan, Naramig, Zomig, Zolmitriptan, Maxalt, Rizatriptan, Almogran, Relpax or Migard.
- Yes
  - No
7. The following question concerns the past three months: Do you alter between using prescription and over-the-counter triptans, and if so, in what way? (SC)
- No
  - Yes, .....
8. What is your **main** reason for buying over-the counter triptans? (SC)
- I don't have to see a doctor and get a prescription
  - I have asked my physician for a prescription but didn't get one
  - I need the tablets immediately
  - Other reasons, .....
9. How often, on average, do you have migraine attacks? (SC)
- More often than once a week
  - More often than twice a month
  - Once or twice a month
  - Less often than once a month
10. How often, on average, do you use triptans to treat your migraine attack? (SC)
- Always → *Question 11*
  - Often → *Question 11*
  - Every second time → *Question 11*
  - Rarely → *Question 11*
  - Never, this is the first time I try this drug → *Question 12*
11. The following question refers to all pharmacies where you buy over-the-counter triptans, **not only this pharmacy**: How often, on average, are you offered help or counselling by the pharmacy staff in connection with your purchase? This includes being asked if you

need any help, if you have used this drug before or what type of headache you have. (SC)

- a. Always
- b. Often
- c. Every second time
- d. Rarely
- e. Never

12. What other drugs do you currently use to treat your migraine? (MC)

- a. None
- b. Acetyl salicylic acid (brand names including Treo, Magnecyl)
- c. Paracetamol (brand names including Alvedon, Panodil, Reliv, Pamol)
- d. Diclofenak (brand names including Voltaren T, Eeze, Diklofenak T)
- e. Ibuprofen (brand names including Ipren, Ibumetin)
- f. Naproxen (brand names including naproxen)
- g. Primperan
- h. Other over-the-counter drug/drugs
- i. Other prescription drug/drugs (apart from potential triptans)

13. Do you get any preventive drug treatment for migraine? (SC)

- a. No
- b. Yes,  
.....

14. Age: ..... years

15. Gender (SC)

- a. M
- b. F

Thank you for participating!

## Appendix III

Interview guide focus group interviews (paper IV) *Author's translation*

### About the intervention itself

- Can you describe what StatinStödet is, to you?
  - How does it fit in the everyday work flow at the pharmacy?

### Information/knowledge

- Think back to when the project started: From where did you get information about the project?
  - Did you miss anything?

### Areas of improvement

- How would you design StatinStödet, if you were to change it?
- How would you like to help patients with chronic drug treatment to achieve a better drug utilisation?
  - What kind of support do patients want from the pharmacy?

### Co-operating with healthcare, how? (added after two focus group interviews)

- *Purpose?*
- *Advantages/disadvantages?*

### Co-operating with other retail pharmacy chains/pharmacies, how? (added after two focus group interviews)

- *Purpose?*
- *Advantages/disadvantages?*

### Research

- Are you aware that StatinStödet is being evaluated in a research project?
- What do you think about research (in general) and research on pharmaceutical services (in particular)?

### Closing remarks and Thank you

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